DEVELOPMENT OF TRAINING AND SUPPORT FOR PARENTS WHO PERFORM SPECIALIST MEDICAL CARE AT HOME

Bethan Page

Kellogg College

University of Oxford

TRINITY TERM 2021

Thesis submitted for the degree of Doctor of Philosophy in Experimental Psychology

ABSTRACT

Complex medical care is now performed by families at home, and is no longer solely the domain of healthcare professionals working in hospitals. Parents caring for children with serious or chronic conditions perform a range of medical procedures for their children, including caring for children with feeding tubes and children who need support with breathing (children dependent on long-term ventilation). This thesis examines the challenges and risks of complex medical care for children at home, and explores how best to train and prepare parents to provide this care, drawing upon relevant psychological theory and the lived experience of families. The first section of the thesis explores the clinical issues: Chapters 3 and 4 examine the safety concerns of clinicians who support families at home through analyses of incident reporting data, and Chapters 5 and 6 explore the experiences of parents caring for children with complex medical needs through interviews and surveys. This first section reveals a clear need to improve training and support for families. The second section (Chapters 7-9) consists of a series of experiments on how findings from psychology could inform the development of training interventions for parents caring for children with gastrostomies (a type of feeding tube). There was a significant benefit of supplementary videos and images on parents' learning, but limited benefit of retrieval practice. Schema-enhanced training had a detrimental impact on performance in a test of knowledge. In the final section (Chapters 10 and 11) I develop and evaluate a package of training and support for parents caring for children with feeding tubes which has now been implemented across Oxfordshire and the Thames Valley. The training package consists of a library of videos to support families from referral for a gastrostomy through to the first few years caring for their child at home. Survey data from families and clinicians confirm the value of the library of videos for educating and empowering families.

Acknowledgements

I am extremely grateful to Professor Charles Vincent for his mentorship and guidance throughout my DPhil. Your experience and kindness have been invaluable, and you have always supported me to do research which has a real impact. Thank you to Professor Nick Yeung, my second supervisor, for all you have taught me about experimental design and statistics, and for your genuine interest in doing something of practical value, and helping me grapple with the challenges of jumping between experiments and the real world.

To Dr Emily Harrop and Mr Alex Lee, you have both been extraordinary clinical mentors. Without your support, much of this DPhil would not have been possible. I have huge admiration for the support you give to children and their families, and your drive to improve services even in the unprecedented pressures of a pandemic.

I am immensely grateful to all the families who have contributed to my research, especially to Tania and Dylan, and to Katherine, who have supported my work from the start. Thank you to Tania and to Dylan for being the star of the videos. I was humbled by the many parents who offered to help us film videos, driven by a desire to help others.

I would also like to thank the wonderful Siobhan and Colette. You are both brilliant presenters in the videos, and so empathetic to the needs of the families you support. To all the other healthcare professionals who have supported this work, I am so grateful for your help. To Alison and Karen, and all the other nurses whose expertise has been critical to developing the videos.

I would also like to thank the team at OxSTaR for your support. I am grateful for all the critical organisation and admin work you did to support the Health Foundation funding which enabled us to develop the training package.

I must also thank my wonderful friends and colleagues in the Risk and Safety lab. To Rasanat, whose support was critical to the first two studies analysing incident reports (Chapters 3 and 4). Thank you for your perseverance grappling with the messy NHS data. Thank you also for your help filming the early videos, and for our shared laughter as we tried to practice doing the procedures on the mannequin! Thank you to Gurpreet and Eirini, my friends and colleagues: I miss our chats and lunches together very much. To my more recent colleagues, David, Keegan, Ruta and Mia, thank you for listening to me at the various stages of my thesis chapters and helping me shape up my ideas. I have missed your company so much while working at home throughout the pandemic.

Finally to my family. To my husband Ben, who has unexpectedly been stuck in the house 24-7 with me for much of the last 18 months during lockdowns. Thank you for keeping me sane, and for always being there to encourage me and make me laugh. To my brother Carlo, who has shared the trials and tribulations of his own PhD journey alongside me. Finally to my parents, thank you for all your encouragement and supporting me to do a job I really care about, and to my 91 year old grandad, who has even read some of my papers!

Abbreviations

CCN	Community Children's Nurse
CPD	Continuing Professional Development
GJ tube	Gastrojejunostomy (GJ) tube
IV antibiotics	Intravenous Antibiotics
JR	The John Radcliffe hospital
NG tube	Nasogastric Tube
NHS	National Health Service
NRLS	National Reporting and Learning System
OxSTaR	Oxford Simulation, Teaching and Research Centre

Table of Figures

Table of Tables

Contents

Chapter 1 An introduction to complex healthcare at home

1.1 Introduction

As a result of rapid medical advancements, millions more adults and children are living with chronic conditions, many of whom would not previously have survived. Amid growing pressures on hospitals, increasing numbers of patients with complex medical needs are now cared for at home (Fraser et al., 2012; Institute for Healthcare Improvement, 2018; Ten Haken, Ben Allouch, & Van Harten, 2018; Vincent & Amalberti, 2016). It is government policy to ensure care is provided at home rather than in hospital wherever possible (Department of Health, 2011; HM Government, 2008). Whilst services such as community nurses, hospital-at-home services and paid carers help with home care, the majority of care is typically provided by families.

This DPhil focuses on care at home for children with complex medical needs. Many more children are surviving premature birth, complex congenital abnormality, inherited or acquired disease and major trauma (Whiting, 2019). Their parents carry out complex medical procedures for them at home, amongst other responsibilities such as co-ordinating care and managing equipment, medications and supplies. This thesis examines the challenges and risks of complex medical care for children at home, and explores how best to train and prepare parents to provide this care, drawing upon relevant psychological theory and the lived experience of families. This first chapter presents an overview of care at home for children with complex medical needs. The second introductory chapter explores how psychological theory can inform how we train and prepare parents for the significant responsibilities they undertake. This first chapter describes the types of healthcare procedures now performed by families at home, some

example summaries of children's clinical needs, a descriptive of what is known about the parents' experiences and the impact on families, and then discusses the broader benefits and risks of families providing care at home. The aims of the thesis are stated at the end of the chapter.

1.2 Care at home for children with complex medical needs: An overview

The number of children with complex medical needs is rapidly increasing (Fraser et al., 2012; McDougall, Adderley, Wensley, & Seear, 2013; Stoll et al., 2010; Ten Haken et al., 2018). This includes technology-dependent children who require medical equipment to support vital bodily functions, such as eating and breathing (Ten Haken et al., 2018), and children with severe chronic conditions and life-limiting conditions, such as children with congenital anomalies, malignant tumours or severe neurologic conditions with marked functional impairment (Fraser et al., 2012). One definitional framework from the US defines children with medical complexity in terms of: i) substantial family-identified health care service need and impact on family, ii) chronic condition(s) that are severe and/or associated with medical fragility, iii) severe functional limitations (such as the need for a tracheostomy or feeding tube) and iv) high utilisation of healthcare resources (E. Cohen et al., 2011). It is government policy to ensure these children are cared for at home as much as possible (Department of Health, 2011; HM Government, 2008).

It is difficult to find exact estimates of prevalence, as definitions vary and national data is not always available. To give some indication, the number of children in the UK dependent on home ventilation (mechanical aids for breathing) increased from 93 children in 1990, to 844 in 2008 (Wallis, Paton, Beaton, & Jardine, 2011), with a national report from 2020 identifying 3061 children and young people, which the authors advise is

an underestimate (The National Confidential Enquiry into Patient Outcome and Death, 2020). In a report by the British Artificial Nutrition Survey, it was estimated that there were 16,982 children on home enteral nutrition (tube feeding) in the UK in 2010, with an increase of 41.5% between 2005 and 2010 (BAPEN, 2011). A recent report estimated that there are 86 625 children with life-limiting conditions in England in 2017/18, up from 32,975 in 2001/02; this is a 2.6 fold increase over 17 years (Fraser, Gibson-Smith, Jarvis, Norman, & Parslow, 2020). The rising numbers of children with complex medical needs are a challenge for developed healthcare systems globally (Berry, Agrawal, Cohen, & Kuo, 2013; Bucholz, Toomey, & Schuster, 2019). A study from the US estimated that children with medical complexity account for 1% of the paediatric population but over a third of paediatric healthcare spending, predominately through expensive hospital stays (E. Cohen et al., 2012).

These children often have a substantial network of professionals involved in their care. This may include: multiple specialist consultants, specialist hospital nurses, surgeons, GPs, community children's nurses (CCNs), community paediatricians, community dieticians, physiotherapists, school/nursery nurses, speech and language therapists (SALT) and palliative care and respite teams. There has been a rapid growth in community and specialist hospital services to support these children (Carter et al., 2012; Department of Health, 2011; Whiting, 2019). For example, the number of Community Children's Nursing (CCNs) Teams in England increased from less than 60 in 1994 to 200 in 2009 (Whiting, Myers, & Widdas, 2009).

It is recognised that the quality of services for these children is highly variable across the country (Department of Health, 2011). For many of these children, mainstream

healthcare services lack the expertise to help e.g. GPs, A&E and Out of Hours (Fleming, Wright, MacAuley, McCann, & Madigan, 2007; Whiting, 2019). Access to services is of particular concern out of hours, when accessing help from specialist staff can be difficult (Whiting, 2019). Despite this large network of professionals, the primary responsibility for managing the child's care lies with the parents (Whiting, 2019). There is a growing recognition that the system is poorly co-ordinated and that too much of the burden of care is being shouldered by parents (Berry et al., 2013).

1.3 The types of care now carried out at home

Medical devices now used by family carers at home (including parents caring for children) range from meters and monitors such as blood pressure monitors, to complex devices which support vital bodily functions including respiratory equipment (e.g. ventilators), feeding equipment (e.g. feeding tubes and pumps) and treatment and therapy equipment (e.g. infusion pumps and dialysis equipment) (National Research Council, 2010). Historically family members have helped young children and older adults with activities of daily living, such as helping with dressing, eating and bathing, but nursing and medical tasks were once solely the domain of nurses and doctors. We are seeing a dramatic transformation in the type of care undertaken by family caregivers at home (Levine, Halper, Peist, & Gould, 2010; Moorman & Macdonald, 2013). A study of over 1000 family caregivers found that 43% do medical tasks, such as changing dressings, administering multiple medications and helping with feeding tubes (Donelan et al., 2002). A quote from a family caregiver in a recent report from the Institute for Healthcare Improvement (IHI) illustrates the changing demands put on family caregivers:

"*Infusion therapy devices. Oh my goodness. How did that become something that you manage in your own home? That's crazy."* — Family caregiver [Institute for Healthcare Improvement, 2017]

Box 1.1 gives a short list of specialist medical procedures which are carried out by parents who care for children with severe chronic and life-limiting conditions. The next section will explore two specific tasks in detail: enteral tube feeding, and long-term ventilation. These tasks are the subject of later chapters in the thesis.

Box 1.1: Examples of specialist medical care now carried out at home

Enteral tube feeding (via nose, stomach or bowel)

Parenteral nutrition (intravenous administration of nutrition)

Oral and nasal suctioning

Oxygen or high flow nasal cannula therapy

Tracheostomy care (breathing tube)

Invasive ventilation (via a tracheostomy)

Non-invasive ventilation (e.g. via face mask or nasal cannulae/nasal pillows)

Catheter care

Intravenous injections

Subcutaneous injections

Stomas

1.3.1 An example of a common, lower risk type of care: enteral tube feeding

Feeding tubes are common, but relatively low risk in comparison to some other types of care carried out at home such as tracheostomy care or parenteral nutrition. Enteral feeding, feeding through the nose, stomach or bowel, is commonly used to provide nutritional support to children with severe chronic illnesses and neurodisability who have difficulty swallowing or cannot get adequate nutrition through eating and drinking orally (Burdall, Howarth, Sharrard, & Lee, 2017). There are several types of enteral feeding, all of which involve inserting a feeding device into the stomach and/or jejunum. Nasogastric (NG) tube feeding (via the nose) is the most common short-term solution. Surgically placed devices are required in children with longer-term feeding needs, such as a gastrostomy tube, gastrostomy low-profile 'button' or jejunostomy where feeds are delivered directly in the stomach or bowel. Parents administer feeds, water and medications to their children via the tube. For surgically-placed tubes such as gastrostomies, parents have to learn to care for the stoma site, e.g. by cleaning it, as well as manage complications such as infections and leakage. Parents may also learn to replace NG tubes or gastrostomy buttons themselves. For further information about these tasks, please see Appendix 1.

1.3.2 An example of rarer but higher risk type of care: long-term ventilation and tracheostomy care

Tracheostomy care and long-term ventilation are much less common than enteral feeding, but carry much greater risks. Long-term ventilation is a mechanical aid for breathing, used either invasively by tracheostomy or non-invasively via a mask interface for all or part of the 24 hour day. Level 3 ventilated children are unable to breathe without the support of the ventilator. Level 2 ventilated children would survive accidental

disconnection but would be very unwell, and Level 1 ventilated children can breathe unaided and use ventilation for support (Cooke & Harris, 2011). A tracheostomy is an artificial opening into the windpipe (trachea) which is held open by a tracheostomy tube. Air goes in and out through the tracheostomy tube and bypasses the nose and mouth. Family carers who care for a child with a tracheostomy learn to perform various tasks including removing excess secretions by suctioning, changing the tapes which hold the tracheostomy tube in place, caring for the skin around the stoma site and organising equipment and supplies (Amin et al., 2017). They also do routine tracheostomy changes, and emergency changes if the tracheostomy is pulled out or becomes dislodged or blocked. Some children with tracheostomies breathe through their tracheostomy, but others need the support of ventilators to allow them to breathe. Likewise not all children who need ventilation also have tracheostomies. Cases of accidental death have been reported in the literature (Edwards, Kun, & Keens, 2010). Ventilation and tracheostomy care are thought to be the most complex type of care provided by families in the home.

1.4 A clinical summary of children's needs

There are many different trajectories for children with complex medical needs. Some children may be medically complex from birth, e.g. born with complex congenital abnormalities. Some of these children may have multiple successful surgeries early in life resulting in few ongoing needs later in childhood. Other children become more medically complex over time, for example children with neurodegenerative diseases, and may die in childhood. Less commonly, children can become suddenly medically complex, e.g. after major trauma. The trajectories of these children vary; they may be in hospital for months

Box 1.2: Example summary of three children's clinical needs over time

Child X: A child with a neurodegenerative disease who became more medically complex over time

Child X was diagnosed at 15 months old with a neurodegenerative disease. He was non-verbal and non-mobile. He ate solid food for a while but then one day lost the ability to feed and needed a nasogastric feeding tube. He struggled with reflux and needed multiple surgeries and had ongoing bowel issues. He later had gastrostomy surgery to support his nutritional requirements. He had regular urine infections and ear infections with multiple admissions to hospital to treat them. He needed an enema, and later needed catheters when he lost the ability to pass urine. He died aged 7.

Child Y: A child with a rare congenital condition who became less medically complex over time

Child Y was diagnosed a few days after birth with Tracheo-Oesophageal Fistula (TOF) and oesophageal atresia (OA). This is a rare congenital condition which affects the oesophagus (food pipe) and/or trachea (airway). She was born unable to swallow saliva or milk. She needed intensive neo-natal care prior to corrective surgery, and multiple follow-up hospital visits for further treatment. After a few months in hospital, she was discharged home with a nasogastric tube for feeds, and later needed a gastrostomy. Now aged 6 she is able to eat and drink, but has to be careful to eat slowly and drink lots during meals. As a result of her tracheomalacia (caused by a floppy trachea) she has a harsh, barking cough and has difficulty shifting secretions during a viral illness such as a cold. She is very susceptible to chest infections. She continues to need anti-reflux medication.

Child Z: A child born prematurely with multiple chronic conditions, dependent on multiple medical technologies

Child Z was born prematurely at 24 weeks and is also a twin. She has cerebral palsy, scoliosis, epilepsy, gut motility disorder, chronic lung disease, dystonia, restrictive respiratory disorder and auditory neuropathy. She has a tracheostomy, is fed via a jejunostomy 22hrs per day with a gastrostomy on continual free drainage and is ventilated overnight. She currently needs oxygen all the time. She also has a baclofen pump and a port a cath. She has a large amount of medications over a 24hr period with a detailed dystonia/seizure escalation plan and pain management plan to manage if and when she needs rescue medications, pain relief etc. Her care is 24hrs and often 2-1. Her tone and airway can be very unpredictable. She needs suctioning (nasal/oral/tracheostomy). Her tracheostomy needs changing weekly and her gastrostomy and jejunostomy buttons needs replacing every 3 months. She uses a ventilator (pressure support) and needs clearway cough assist and chest clearance physiotherapy treatment. She needs a catheter due to urinary retention and bladder dysfunction. She has medication administered via her jejunostomy, orally and rectally and nebuliser treatment 3 - 3xper day. She is doubly incontinent.

or years after birth, and many have multiple hospital stays for surgeries or acute admissions. Box 1.2 illustrates example clinical summaries for three different children.

1.5 The parent journey

As shown in Box 1.2, it is quite common for parents of children with complex medical needs to manage multiple types of care and for their child's needs to change over time. This next section looks at what is known about the experiences of parents caring for them.

The initial months of providing complex care for a child can be scary and overwhelming. Family members have a steep learning curve and often worry about making mistakes (McDonald, McKinlay, Keeling, & Levack, 2015; Spiers & Beresford, 2017). Parents can feel tension between their role as a "nurse" and their role as a parent (Kirk & Glendinning, 2004). Many of the tasks parents perform can be distressing or painful to the child, such as invasive procedures like changing a gastrostomy button or a tracheostomy. Parents have the difficult task of doing medical procedures which they know are in their child's best interest, but inflict pain or discomfort on their child. It can be difficult for young children to understand why their parent has to inflict pain on them. Parents have to manage their child's distress as well as their own emotions (McDonald, McKinlay, Keeling, & Levack, 2016; Spiers & Beresford, 2017).

There can also be substantial changes to the physical environment in the home, with medical equipment and supplies in the living room and child's bedroom (Kirk & Glendinning, 2004). These physical alterations to the home can have a significant psychological impact on families (Mitchell, 2020), with one mother describing her child's bedroom as a "mini-hospital" (Kirk & Glendinning, 2004). A recent campaign by the

children's charity Well Child involves the sharing of videos via social media of daily life for families with a child with complex medical needs. The videos clearly portray the complex medical routines families carry out, the physical changes to the home and the reality of life for these families (Well Child, 2018). A paper analysing the content of these videos outlines some common themes experienced by families including constant need for vigilance and the feeling of being "different" from other families (Carter, Bray, Keating, & Wilkinson, 2018). There are substantial emotional and practical changes that families need to adjust to.

1.5.1 Initial preparation and training of parents

Many of the tasks carried out by parents are beyond the training of many nurses and doctors. Healthcare professionals on hospital wards and intensive care units receive years of university training, practice-based training and ongoing continuing professional development (CPD). Healthcare professionals in hospitals also have on-site backup and support, whereas family carers are often home alone whilst carrying out medical tasks (Reinhard, Levine, & Samis, 2012). Despite this relative lack of training and support, many studies have shown that family carers develop substantial expertise in carrying out medical procedures through repeated practice, and develop substantial expertise in the needs of their child (Hinton & Armstrong, 2020; McDonald et al., 2016; Schubert, Wears, Holden, & Hunte, 2017). Parents are typically taught to perform the medical procedures their child needs by nurses in hospital and in the community. A study of 26 family carers characterises learning into three stages: i) an initial concentrated period of training, ii) taking day-to-day responsibility while continuing their learning and iii) the development of expertise through time and experience (McDonald et al., 2016). In general there is very

limited monitoring of parental skills and knowledge, and unsurprisingly there is some evidence of gaps in the knowledge and skills of some parents.

A series of studies observing parents caring for children with NG or gastrostomy tubes at home found a number of safety concerns, including irregular checking of tube position and deterioration in hygiene practices over time (Evans, Holden, & MacDonald, 2006; Evans et al., 2012, 2010). Another study found that a quarter of parents had misplaced a nasogastric tube at least once (Northington, Lyman, Guenter, Irving, & Duesing, 2017). If a nasogastric tube becomes misplaced and ends up in the lung (rather than the stomach) it can cause severe harm or death (NHS Improvement, 2016). In a survey with parents and nurses on unexpected situations with tracheostomies or ventilators in the home, 63% did not know about alarms related to accidental dislodgement of the tracheostomy tube and 52% failed to understand high-pressure alarms and mucous plugging (Kun, Davidson-Ward, Hulse, & Keens, 2010). Information on quality control of ventilator care in the home has shown that only 56% of hospitals initiating home ventilation assessed whether patients or caregivers cleaned and operated the ventilator equipment correctly after discharge from hospital (Margolan, Fraser & Lenton 2004; Lloyd-Owen et al., 2005). Findings from the literature indicate that there are substantial variations in the provision of training for parents, and limited monitoring of competency by the healthcare system, certainly in comparison to the monitoring of skills of those paid by the system to deliver care.

1.5.2 Support for parents

There is a relatively large literature on the burden of care on parents caring for children with complex medical needs (Berry et al., 2013; Kuo, 2011; Lee & Lynn, 2017). A

systematic review found that parents caring for children with chronic conditions are significantly more stressed than parents caring for healthy children, and that greater stress is associated with greater parental responsibility for treatment management needs (Cousino & Hazen, 2013). A recent comparative cohort study found that mothers of children with life-limiting conditions and chronic conditions have a higher incidence rates of various common and serious physical and mental health problems, and were also found to be at higher risk of death from all causes (Fraser et al., 2021). Parents also often experience financial difficulties (Paget & Cadywould, 2015; Thomson et al., 2016). Many parents have to give up work or experience difficulties finding flexible employment (Kish, Newcombe, & Haslam, 2018). Studies also report problems with access to respite services (Lee & Lynn, 2017; Sobotka et al., 2019) and with social isolation (Lee & Lynn, 2017). Medical routines, the need for constant vigilance and frequent medical appointments place significant time demands on parents (McCann, Bull, & Winzenberg, 2012). Whilst some families are able to access care packages (which provide paid carers for a set number of hours a week), in nearly all cases the vast majority of care is provided by family members; unlike healthcare professional who work shifts, parents can be on duty 24-7 (Whiting et al., 2009). Some families have to be alert at night, for example to spot any problems such as alarms sounding on ventilators. Sleep disturbance is a common problem for families with technology-dependent children, and has been found to be associated with fatigue and depression (Keilty, Cohen, Spalding, Pullenayegum, & Stremler, 2018). Sleep disturbance is also a safety risk as it can affect parents' ability to provide safe and high quality care. A recent systematic review concluded that sleep deprivation has substantial effects on parents with children with complex needs and can affect their emotional wellbeing and relationships (McCann, Bull, & Winzenberg, 2015). A

key contributing factor to sleep deprivation was the need to be vigilant during the night (McCann et al., 2015).

1.5.3 Co-ordination of care

Co-ordinating care is a time-consuming endeavour for many parents and adds to the burden of care. Children with complex medical needs typically have a substantial number of professionals involved in their care. This can result in a complex timetable of appointments for parents to manage (McCann et al., 2012) and often problems in the co-ordination of care including poor communication between services (Altman, Zurynski, Breen, Hoffmann, & Woolfenden, 2018). In a large interview study with healthcare professionals, many professionals reported that the system often relies on parents to co-ordinate a lot of the care, regardless of a family's capacity to do so (Altman, Zurynski, et al., 2018). Studies from multiple different countries have found that parents feel they are fighting the system (Currie & Szabo, 2019; Dybwik, Tollåli, Nielsen, & Brinchmann, 2011). There are many frustrations for parents trying to navigate complex health and care systems. Various models and service improvements have been proposed and implemented to try to integrate care and reduce the burden of care for parents co-ordinating care (Altman, Breen, et al., 2018; Hillis, Brenner, Larkin, Cawley, & Connolly, 2016; Pordes, Gordon, Sanders, & Cohen, 2018). However there are no easy solutions, and little consensus on the best models. Paediatric services were not originally designed to meet the needs of the growing population of medically complex children: the changing demographic in paediatrics of more medically complex children is causing various pressures across the healthcare system (Cass, Barclay, Gerada, Lumsden, & Sritharan, 2019). Meanwhile families have to work hard to co-ordinate care, understand the system and make it work for their child.

1.6 The benefits of home care

While previous sections have highlighted the burden for parents and the problems that may arise, we should also appreciate the many benefits of home care for families and the wider healthcare system. There are many benefits beyond the need to reduce demand on overstretched hospitals. Patients, both old and young, are discharged sooner from hospital, with more complex ongoing needs. Length of stay is rapidly decreasing: the average length of stay in an NHS hospital has fallen by more than 40 per cent from 8.4 days in 1998/9 to 4.9 in 2015/16 (Ewbank, Thompson, & McKenna, 2017). This is positive in many ways as the primary aim of many patients and families is to spend as little time in hospital as possible. Patients often prefer to be in the comfort of their own home, spend time with their family and to be as independent as possible. For example, babies born prematurely now go home much sooner than they would have done previously, but with more complex ongoing needs, for example still needing a NG tube for feeding (van Kampen et al., 2019). For parents caring for children with complex medical needs, having the child at home means the family can spend more time together and the child can participate in family life and education. Children report negative social aspects of hospital admissions such as feeling lonely (Schalkers, Dedding, & Bunders, 2015) and they often miss out on education. Daily visits to hospital are disruptive to family life and parental employment and can negatively impact other siblings, who may need to be cared for by other family members or babysitters or taken on daily visits to the hospital. Hospital admissions are also very expensive for families, with hidden costs such as transport, parking, babysitters for siblings and food costs (DiFazio & Vessey, 2011; Mumford et al., 2018). Home care has many benefits.

Home enteral feeding is enabling many children to be discharged from hospital sooner (including babies born prematurely), and reduces the risk of malnutrition-related complications for children who cannot get their nutritional requirements orally (Rosen et al., 2016; Sullivan, 2014). Gastrostomies can have benefits for a child's physical health, gastrointestinal symptoms, sleep, time spent feeding and the emotional health of the child and family (Maddison et al., 2021). There are also many benefits specific to long-term ventilation at home. For some children it is a bridge to recovery, for example to allow a child to grow or develop until they recover or are strong enough for further treatment or surgery (Ray et al., 2018). For others, it is a life-sustaining treatment and may be used, for instance, to allow a child to be discharged from hospital as part of palliative care or to keep them alive long enough to reach their developmental potential. Long-term ventilation can reduce the frequency and duration of readmissions to hospital, improve quality of life and quality of sleep (Katz, Selvadurai, Keilty, Mitchell, & MacLusky, 2004).

1.7 The risks of home care

The problems described in earlier sections are not unique to families caring for children with complex medical needs, but part of a more general phenomenon arising from providing complex medical care outside of hospitals. There is an emerging literature on the safety of care at home (Institute for Healthcare Improvement, 2018; Vincent & Amalberti, 2016). Adverse events are events which result in unintended harm to a patient caused by medical management, rather than by the underlying disease (Brennan et al., 1991; Masotti, McColl, & Green, 2010). Adverse events may lead to longer stays in hospital, readmissions, disability or death. The incidence and nature of adverse events in hospital has been extensively studied around the world (Baker et al., 2004; Brennan et al.,

1991; Vincent, Neale, & Woloshynowych, 2001). More recently, studies have looked at adverse events in home care. Two studies, one conducted in the USA (Madigan, 2007) and the other in Canada (Sears, Baker, Barnsley, & Shortt, 2013), found that 13% of home care patients experienced an adverse event. Larger estimates based on expert chart review of 1200 patients discharged in 2009–2010 in Canada showed a rate of 4.4 % adverse events (Blais et al., 2013). The most frequent were injuries from falls, wound infections, behavioural or mental health problems and adverse outcomes from medication errors. A recent systematic review estimated that rates of medication administration errors from carers ranged from 1.9 to 33% of medications administered (Parand, Garfield, Vincent, & Franklin, 2016). These included dosage errors, omitted administration, wrong medication and wrong time or route of administration. Patients cared for at home are at risk of suffering adverse events, just as patients cared for in hospital are.

As well as risks to patients, there are also risks to family carers. Family carers are at high risk of burnout, depression and chronic stress (Cousino & Hazen, 2013; Dalton, Thomas, Harden, Eastwood, & Parker, 2018). More complex care has been found to be associated with greater carer strain (Moorman & Macdonald, 2013). Unlike professionals, there are no restrictions on the hours worked by family carers. Sleep deprivation has been found to be a common problem, which has long-term health consequences, and increases the risk of errors when providing care, e.g. through lapses of attention or memory deficits (Keilty et al., 2018; McCann et al., 2015).

As well as these more general adverse events, technology-dependent patients (patients who rely on medical devices for vital bodily functions) are also vulnerable to other risks

such as equipment malfunction, and inadequate training of family members and other carers operating the equipment. Common complications for gastrostomies include over-granulation (i.e. an excess of granulation tissue which can prevent the stoma site from healing, often appearing as a red, bumpy tissue that can bleed), infection or leaking around the stoma site, and broken or blocked gastrostomy tubes (Crosby & Duerksen, 2005; Puntis, 2009). Almost 10% of patients visited the emergency department or were readmitted to hospital within one month of gastrostomy surgery (Goldin et al., 2016). There are also rare but life-threatening risks such as peritonitis following displacement of a gastrostomy device (Healey, Sanders, Lamont, Scarpello, & Agbabiaka, 2010; Taheri, Singh, & Duerksen, 2011). For NG feeding, there are ongoing concerns in hospitals and in the community about the risk of feeding through a misplaced NG tube into the lung, with 32 deaths reported across the NHS between 2011 and 2016 (NHS Improvement, 2016). It is common for babies to pull NG tubes out; with frequent tube replacement there is an increased risk of misplacement (Rosen et al., 2016). There are very significant risks involved in long term ventilation, including accidental disconnection of the ventilator or decannulation of the tracheostomy which can result in death. Cases of accidental death have been reported in the literature (Tibballs et al., 2010).

The balance of benefits and risks of home care is not static but hugely dependent on how well families are trained and supported. Many of the risks arising from medically complex home care could be mitigated if we could consistently provide high-quality preparation and support to families. It is important that all those providing care at home can safely manage the routine care required, and are also adequately prepared to manage high-stakes emergencies which can happen at any time, such as blocked or dislodged tracheostomy tubes or ventilator malfunction. Parents need support from the healthcare

system to ensure the burden of care and emotional demands are manageable, including access to respite care and care packages. Preparation and support for parents caring for medically complex children needs to be given the same, if not more attention as we give to training and supporting healthcare professionals.

1.8 Aims of the thesis

We have seen in this first chapter that care in the home is becoming more medically complex, and is primarily delivered and managed by families. This chapter has examined the experiences of parents caring for children with complex medical needs and outlined some of the benefits and risks of complex care at home. This thesis will look at the challenges and risks of complex medical care at home for children, (in particular in relation to enteral feeding and long-term ventilation), and explore how best to train and prepare parents to provide this care, drawing upon relevant psychological theory which will be discussed in the next chapter.

The aims of this thesis are to provide:

- A greater understanding of the safety issues and risks of home care for children with complex medical needs (Chapters 3 and 4)
- A greater understanding of parents' experiences of providing complex medical care for children are home (Chapters 5 and 6)
- To develop and test interventions to better prepare and support parents caring for children with complex medical needs, drawing upon relevant psychological theory and the lived experience of families (Chapters 7, 8, and 9)
- To develop and evaluate a training package to prepare and support parents to care for children with gastrostomies (Chapters 10 & 11)

Finally a review of the findings from the thesis will be presented, alongside recommendations for further research and policy change.

Chapter 2 What can Psychology tell us about how to train and prepare parents to perform complex medical procedures?

2.1 Introduction

This chapter examines relevant psychological literature, and explores the implications for how to train and prepare parents to provide complex medical care. As we saw in the first chapter, families are increasingly asked to perform complex medical procedures at home, such as feeding tube care or tracheostomy care, which require them to remember complex medical information and develop new skills. Parents caring for medically complex children need high-quality training and support, or there is a serious risk that their children will come to harm. Later in my thesis I develop a package of training and support for families caring for children with gastrostomies. The training package draws on tools for improving learning and memory shown to be effective in experimental studies of learning and developing expertise (explored in this chapter, and through experiments in Chapters 7 - 9), as well as findings from the lived experience of families (explored in Chapters 5 and 6). The present chapter serves as a foundation for later chapters which develop and test training interventions (Chapters 7 – 11). In this chapter I first briefly describe how training is currently delivered to parents, and how this contrasts with training for healthcare professionals. The chapter then explores a range of factors which might influence how information is encoded, before exploring factors which influence how skills are developed and maintained. The last section of this chapter discusses some of the limits to the transfer of findings from experimental studies to the real-life context, which is one of the key themes in my thesis.

2.2 How is training currently delivered to parents?

This first section presents a brief summary of how training is currently delivered to parents who perform medical procedures for their children at home. Chapter 6 will examine parents' experiences of training in more detail through surveys with parents across the UK. Parents learn to provide medical care to their children through experience, with varying levels of formal and informal teaching, typically from nurses (McDonald et al., 2016). Figure 2.1 describes the pathway for training parents whose children need a gastrostomy (developed through discussions with lead clinicians for gastrostomy care across the Thames Valley). As this pathway illustrates, training is mostly in the form of written information booklets, verbal information from clinicians and demonstrations from nurses. Clinicians provide parents with varying amounts of information and demonstrations in hospital, and varying levels of follow-up support and teaching from community nurses (CCNs) once the family are home. Hospital admissions for gastrostomy care are typically only around two days long, whereas children with tracheostomies and other more complex care may have much longer hospital admissions with more time for training from hospital nurses. Demonstrations and supervised practice are common methods for training parents, as well as written booklets and information on websites. Following initial training, further support and teaching for parents in the long-term is typically ad hoc (McDonald et al., 2016). CCNs sometimes provide further teaching in the community, and families can usually contact them if they have concerns or issues arise. Studies have reported that parents often use online resources as a further source of information post-discharge, as well as Facebook groups (Alderdice et al., 2018; Boland et al., 2016).

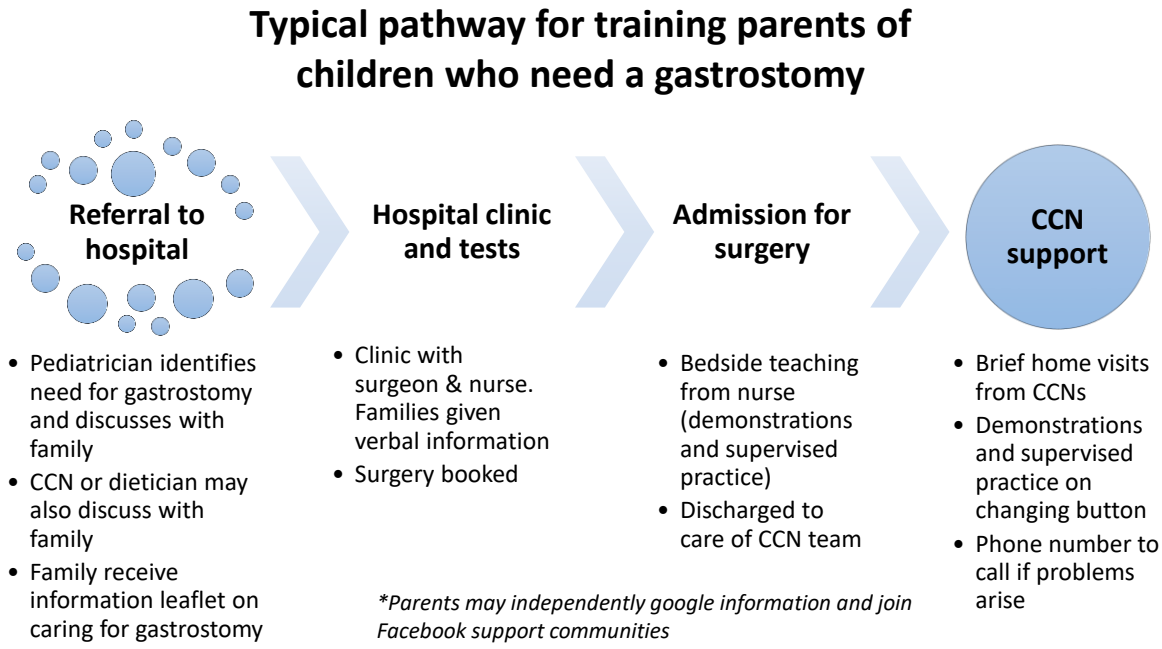


Figure 2.1 Illustrative example of the pathway for children who need gastrostomies across the Thames Valley.

Training for parents contrasts with training given to paid carers or healthcare assistants employed by healthcare services, who are often restricted in the complexity of tasks they are permitted to do. For example, Oxford Health NHS Foundation Trust utilises Shared Care Protocols to identify healthcare tasks which can be delegated to paid-care workers, who are not qualified nurses or doctors. The protocol specifies four levels of complexity of task, with specific requirements for who can perform these tasks, what training they need and how often they need to have their skills reassessed. For instance, Level 3 tasks, such as administering medication, require a specific care worker to receive training for a "named" child from a healthcare professional. Tube feeding and tracheostomy care, and many of the tasks discussed in Chapter 1, are classified as Level 4 tasks. For these tasks, training has to be signed off by a nurse, there is a requirement for annual reassessments of competency, and clear guidelines that must be followed. This is clearly contrasts with

training for parents, where there is very little standardisation of training or assessment, with parents doing tasks at all levels of complexity.

It is also important to compare the training given to parents to the training received by qualified healthcare professionals. Training for parents is in stark contrast to the university training, practice-based training and ongoing continuing professional development (CPD) given to healthcare professionals. Nurses and doctors receive several years of university training and practical placements with designated supervisors. Healthcare professionals often have their competencies reassessed at regular intervals and complete further training in the form of CPD (though the quality and quantity of this CPD varies, varying both across professions and between individual members of profession). Families however typically do not receive any refresher training or have their competency reassessments after discharge from hospital. Families provide care at home, which is an isolated environment compared to working in a team of professionals in a hospital, which is a highly regulated environment with opportunities to seek help from a more senior or experienced colleagues.

There is some literature specifically on what psychology can tell us about how to train medical professionals (Regehr & Norman, 1996; Weidman & Baker, 2015), as well as a much larger literature in the field of Medical Education on how to train healthcare professionals (Grantcharov & Reznick, 2008; Motola, Devine, Chung, Sullivan, & Issenberg, 2013). This is useful background for reflecting on how best to train parents, but there are also some important differences between training medical professionals and training lay people, which affect how their training should be delivered.

2.2.1 Key differences between training parents and healthcare professionals

One important difference between healthcare professionals and parents is that healthcare professionals develop an extensive background knowledge in the anatomy and biochemistry of the body throughout their formal training, and core principles in medicine such as infection prevention and wound care. The vast majority of parents will not have this broad-base expertise, or existing knowledge with which to integrate any new learning. Healthcare professionals learn to perform a wide range of different procedures and to use a range of different devices, which may help with the transfer of knowledge when learning new skills. The nature of expertise, and the background knowledge of healthcare professionals and family carers is therefore very different. Secondly, medical specialisms are developed through years of university teaching, supervised practice and written and practical exams (e.g. objective structured clinical examinations (OSCEs)). Annual reassessments of competencies are common, with regular CPD. This provides healthcare professionals with opportunities to reflect on the gaps in the knowledge, which has metacognitive benefits for learners. For parents there can be limited opportunity to learn from others when providing care at home, when compared to working in a team of other healthcare professionals. Following initial training, further support and teaching for family carers long-term is typically ad hoc (McDonald et al., 2016). A third important difference is the strong emotional connection between parents and children (in comparison to the connection between clinician and patient): parents are typically very motivated learners, but may be more stressed than healthcare professionals when managing emergencies or doing procedures that are distressing for the child. The added anxiety and stress parents experience may affect encoding and recall of information and the performance of skills under pressure.

2.3 How might we incorporate psychological theory into training programmes?

In the next few sections I describe a number of findings from the psychology and education literature and describe how they might be applied to designing training for parents caring for medically complex children. Some of the literature applies to learning medical information and some to acquiring skills. Review articles in the literature which have taken a similar approach to this chapter include reviews exploring the implications from cognitive psychology for classroom teaching (Roediger & Pyc, 2012; Weinstein, Madan, & Sumeracki, 2018), and reviews discussing the implications from psychology for training medical professionals (Regehr & Norman, 1996; Weidman & Baker, 2015). This chapter is not intended to be a complete list of all relevant psychological concepts since the literature on human learning and expertise is immense. Concepts have been selected on the basis of their relevance for training parents. This chapter is illustrative of how we might incorporate psychological theory into training programmes for parents.

2.4 How do we acquire knowledge and learn skills?

The first stage of learning to do a medical procedure, as with the learning of any skill, is acquiring knowledge about the skill, i.e. encoding information. This knowledge may be gained by reading about the skill or task, or through information given verbally (e.g. instructions by a nurse), or by observing somebody else performing the skill. The knowledge acquired acts as a scaffold, from which a skill can be developed. Initially when you learn a new skill, you have to consciously think about each step. Over time, you can perform the skill seemingly without conscious thought. In the first stage, knowledge is declarative ("knowledge that") and later becomes procedural knowledge ("knowledge how") (Anderson, 1982). According to Anderson's influential ACT (Adaptive Control of

Thought) model of skill acquisition, declarative memory consists of facts (e.g. pH testing is used to check the position of a nasogastric tube), whereas procedural knowledge is represented by productions (e.g. how to insert a nasogastric tube) (Anderson, 1982). Instructions for a skill are initially stored in declarative memory and later are stored as productions, conceptualised as "if then" rules that we no longer consciously think about when we are performing the skill. The production compilation mechanism gradually transforms memory retrieval of task knowledge (declarative memory) into direct perception–action mappings (procedural knowledge). Skills begin with knowledge acquisition. The following sections of the chapter focus on strategies to improve the first stage, the encoding of information, with the later sections in this chapter focusing on the development of cognitive and motor skills.

2.5 Encoding declarative information

Studies in cognitive psychology have explored the factors that predict successful retrieval of information after initial encoding. These experiments typically use simple stimuli like lists of words, but also sometimes longer texts. These studies have revealed various factors that have been translated into education research, which have some obvious applicability to the context of learning medical information which is the first stage of training for parents. Memory is not simply a reproduction of information but rather a dynamic process where new information is integrated with existing information at the time of encoding and reconstructed at the time of retrieval. In the next section I explore factors widely reported to predict successful retrieval of information and the implications for parents learning medical information.

2.5.1 Schemas and the integration of knowledge

A common misconception about long-term memory is that the capacity of memory is the critical determinant of ability to store new information: too much information and storage becomes full. An alternative view is that long-term memory is less constrained by amount of information to be stored than it is by how well information is organised and assimilated with prior knowledge. According to this view, we forget because we have failed to integrate the new information with our prior knowledge. Schemas are cognitive structures made up of connected items of knowledge, which provide a framework for organising and integrating new information (Alba & Hasher, 1983; Anderson & Pearson, 1984; Bartlett, 1932; Greve et al., 2018). When we generate elaborations (or connections) between our old knowledge and our new knowledge, we create multiple routes for retrieving the learning later, which makes the new knowledge easier to retrieve in the future. Schemas are also critical for applying information to new scenarios based on similar scenarios which have been encountered before, which is essential for problem solving. Schemas and elaborative encoding have been explored in different ways in lab experiments and applied settings. For example, one experiment found that recall was better for a central fact when it was supported by related facts during learning, compared to presenting central fact on their own (Bradshaw & Anderson, 1982). That is, increasing the amount of information to learn actually led to better memory, not worse, at least in the case when the information was meaningfully connected. Other studies have required participants to generate elaborations themselves, e.g. by answering questions about the statements they studied, finding that this process of self-generated elaboration likewise leads to improved memory (Mcdaniel & Donnelly, 1996; Pressley, McDaniel, Turnure,

Wood, & Ahmad, 1987). Depth of processing is thought to be a key determinant of how well information is remembered, with deeper processing (achieved by techniques such as generating elaborations or associations with your prior knowledge) likely to lead to stronger and longer lasting memory traces (Craik & Lockhart, 1972).

There are many different depictions of schemas in the literature (Ghosh & Gilboa, 2014): it is not clear from the literature which of the various techniques used for supporting the development of schemas (e.g. presenting participants with related facts or pictorial images during learning, supporting participants to generate elaborations) are best at helping people to form strong schemas and integrating new knowledge with existing knowledge. There has been limited systematic testing of schema-based interventions in applied contexts and many of the studies cited above use relatively simplistic study materials and rely on small sample sizes. Whilst there are strong theoretical reasons to think schema-based approaches might be useful in the context of teaching medical information to parents, the efficacy of schemas-based approaches in this context is very much unknown.

2.5.1.1 Implications

It follows that parents may benefit from training that helps them to form strong schemas and emphasises links between concepts and relates information to their prior knowledge. Parents are not like healthcare professionals who have extensive prior knowledge on the anatomy and biochemistry of the body, and core concepts in medicine like infection prevention. It is important to understand their existing knowledge base and help them make links between the new knowledge and their existing knowledge. For example, a gastrostomy tract can be described like an ear piercing. Just like when you have your ear

pierced, a new PEG (Percutaneous Endoscopic Gastrostomy) has to be kept clean to prevent infection and turned regularly to prevent 'Buried Bumper Syndrome' (where the internal disc of the PEG tube becomes buried and the stomach lining grows around it). Parents need explanations on why the tasks they are learning need to be done in a certain way. Crucially, they may benefit from receiving more information, rather than less, providing that the extra information encourages the formation of connections and elaborations. This could for example include some background information on fundamental concepts such as infection prevention. The intuition to give only the necessary information may be unhelpful. Helping parents to create strong schemas may also help them to problem-solve when they encounter new scenarios, which were not explicitly taught in training.

2.5.2 Dual-coding

According to the literature on dual-coding, information that is presented alongside complementary images is better remembered than when text is presented on its own (Paivio, 1990). Multiple representations of the same information enhances memory for the information provided the accompanying visual representations are informative and carefully constructed (Mayer, Mayer, & Gallini, 1990). The visual representations can be videos, animations, charts etc. (Mayer, 2002). The pictures and text should have some overlapping content and not just be decorative. The ideas behind dual-coding relate to schemas and elaborative encoding, with pictures and texts providing multiples routes to retrieval and helping to structure information. Visual aids can serve multiple functions, including making the information more memorable (for instance through providing multiples routes to retrieval), making the text easier to understand and providing a

structural framework for the text (i.e. helping with the formation of schemas) (Carney & Levin, 2002). Careful testing would be needed to look at what kind of visual aids are most beneficial in the applied context of interest, i.e. training parents to do medical procedures.

2.5.2.1 Implications

It follows that written information booklets or information of websites for parents should be accompanied by informative visuals, such as diagrams and videos. For example, text or verbal information explaining where a nasogastric tube goes after entering the nose ought to be accompanied by visuals of the anatomy. These visuals could be important to improve parents' understanding of problems with misplacement, such as the risk of it entering the lung. Informative visuals may be a critical addition to the verbal information and written information families are typically provided with as part of their preparation. These visuals may also be in the form of videos which parents can re-watch as needed.

2.5.3 Retrieval practice

We often learn by studying information repeatedly, but re-reading itself has been reported to have limited benefit (Callender & McDaniel, 2009). Retrieval practice, the process of actively retrieving information from our long-term memory typically through a test, has been widely reported to have a large positive effect on memory when compared to restudying material (Karpicke & Roediger, 2008). Testing of information as part of the learning process is a powerful way to improve memory for the information (Roediger & Karpicke, 2006b). Retrieval practice has a dual benefit: it boosts memory for information

accurately recalled and also helps the learner track what they know and do not know, which leads to more targeted study (Roediger & Karpicke, 2006a).

The testing effect has been heavily researched in both lab and real world setting such as small classrooms (Roediger & Karpicke, 2006b). Meta-analyses on the testing effect have reported medium effect sizes in both experimental (Rowland, 2014) and applied contexts (Schwieren, Barenberg, & Dutke, 2017). Testing does not have to be formal exams, it can also be self-tests, small quizzes and answering questions verbally. Feedback on the test (that addresses what you got correct and what you did not and why) increases the size of the effect (Rowland, 2014). There is also some evidence that retrieval practice can protect memory against the negative effects of stress (Smith, Floerke, & Thomas, 2016): in this experiment, performance in the final test was worse in the group who completed the stress-inducing task (giving speeches and solving maths problems in front of judges and peers). However there was no detrimental effects of stress on performance in the final test in the group who has previously completed an intermediary retrieval task. This experiment suggests that the creation of stronger memory representations during encoding through retrieval practice may protect against the detrimental effects of stress on memory retrieval (Smith et al., 2016).

There are a number of boundary conditions of the testing effect reported in recent studies which suggest that researchers in this area perhaps ought to be more cautious about the potential benefits of the testing effect in applied contexts. For example, one study suggests that the testing effect may only hold when the delayed memory test is not very closely related to the questions used in the retrieval practice (Wooldridge, Bugg, McDaniel, & Liu, 2014). Another concerning boundary condition for the benefits of the

testing effect for training families is the finding that the testing effect decreases as the complexity of the study materials increases (Van Gog & Sweller, 2015). Medical information is likely to be seen as complex study materials, and many of the studies on the testing effect have used simple stimuli such as word-pairs which are rarely representative of learning in applied contexts. Without more empirical studies, it is impossible to know whether the benefits of the testing effect will generalize to the applied context of interest (parents learning information about medical procedures).

2.5.3.1 Implications

The testing effect suggests that clinicians teaching parents should use techniques which promote active recall of information as much as possible. Asking questions to check understanding, written tests, self-tests, and asking parents to explain what they have learnt to someone else, may all promote recall. Testing opportunities should ideally include corrective feedback and address any misconceptions. Online tests or self-tests which promote recall could be used as part of a training curriculum. Testing may need to be done in sensitive and low-key manner as it may be intimidating for parents. Retrieval practice may be particularly useful in light of its apparent protective effects on memory where information is encoded under stress, given that many parents learn to do medical procedures while in hospital with their child undergoing surgery and are often stressed in the first few weeks of caring for their children at home.

2.5.4 The spacing effect

The spacing effect is the finding that learning that is spaced out over time is better retained than learning that is massed into a short time period (Smith & Scarf, 2017). The

spacing effect applies both to encoding new information and developing new motor skills. In medical settings, spaced practice has been show to improve retention of surgical skills (Cecilio-Fernandes, Cnossen, Jaarsma, & Tio, 2018; Moulton et al., 2006). For example in one study trainee surgeons were taught a new skill either in one massed training session (1 day) or distributed (weekly) practice regimens. The distributed group performed significantly better on a range of outcome measures including expert ratings of performance (Moulton et al., 2006). The benefits of spacing depend on a number of factors such as the spacing schedule (e.g. is learning spaced out over a few hours or weeks) and the complexity of the task (Smith & Scarf, 2017). Whilst the benefits of spacing out learning seem intuitive, it is difficult to determine how best to employ the benefits of the spacing effect in the context of training parents to do medical procedures and also what level of spacing is acceptable to parents and would work within the constraints of delivering training in a busy healthcare service.

2.5.4.1 Implications

Ideally, training for parents should be spaced out rather than massed into one training session. For some tasks carried out at home, skill acquisition is already spaced out over time. For example, for tasks like nasogastric feeding for babies born prematurely, there can be plenty of time to practice on the hospital ward as the family can be in the hospital for several weeks or months. So, in some situations, the parents may practice caring for their child's nasogastric tube over several weeks, with the support of nurses around them. Parents can begin to take more ownership of the procedures with support around them, enabling them to learn over a period of time. However, for other tasks such as gastrostomy feeding, there is typically very little opportunity for spaced training, as the

surgery is an elective procedure with a 2-3 day stay in hospital, and training is predominately delivered in hospital. There is often pressure to get patients home as soon as possible (Dekonenko et al., 2020). The spacing effect suggests it may be beneficial to provide training in the community prior to the surgery, (e.g. using booklets, videos and simulation dolls) so that the training is not delivered as 'massed training' during a short hospital admission.

2.6 Skill acquisition

In this next section I reflect on factors that support the development of expertise in motor and cognitive skills. Once knowledge is initially acquired in declarative form, it can then be applied and translated into a practiced (procedural) skill. With practice, performing a skill becomes more automatic and less effortful (Ericsson, 2008). However expertise does not just develop over time: amount of experience is not the critical determinant of expert performance. Research on expertise has explored factors which optimise the benefits of practice and the factors which lead to expert performance. This section discusses evidence from studies on deliberate practice for skill acquisition and the role of metacognition in the development and maintenance of skills.

2.6.1 Deliberate practice

Expertise is believed to be developed from extensive practice, but experience itself does not always lead people to become experts (Ericsson, 2004). One view is that the acquisition of expert performance requires engagement in deliberate practice and that continued deliberate practice is necessary for maintenance of many types of professional performance, including performing medical procedures (Ericsson, 2004). Deliberate practice is a structured practice that is effortful, targets areas of weakness and is

designed to improve performance (Ericsson, Krampe, & Tesch-Römer, 2005). The following factors have been found to be associated with increased performance: 1) given a task with a well-defined goal, 2) motivated to improve, 3) provided with feedback, and 4) provided with ample opportunities for repetition and gradual refinements of their performance (Ericsson et al., 1993). For example, repeatedly practising a line of music which you know you find difficult would be deliberate practice, whereas repeatedly playing the whole piece of music from start to finish would not be deliberate practice. Deliberate practice is critical to skill development and the development of expertise. Deliberate practice has been shown to be effective for developing skills in a range of applications in medicine, including surgical skills and medical diagnosis (Ericsson, 2004).

Over the past few decades, deliberate practice has been increasingly implemented into training for healthcare professionals through simulation-based medical education (Motola et al., 2013), which involves 'devices, trained persons, lifelike virtual environments, and contrived social situations that mimic problems, events, or conditions that arise in professional encounters' (Issenberg et al., 2005). A meta-analysis comparing simulation-based medical education (SBME) with traditional clinical medication education reported an effect size of 0.71 for performance on a range of medical and surgical skills (e.g. performance of central venous catheter insertion scored against a checklist) (McGaghie, 2012). Simulation practice need not require mechanically complex equipment—it can often be effective with simple equipment, or "low fidelity" (Maran & Glavin, 2003; Massoth et al., 2019). There are various studies using simulation practice with families caring for children with complex medical needs (Rosenberg et al., 2017; Stanley, Battles Bezruczko & Latty, 2019): the outcomes are often over-stated by the authors, with small sample sizes and reliance on self-report measures which cannot

reliably capture actual learning. The evidence for benefits of simulation practice with family carers warrants further investigation.

2.6.1.1 Implications

Often it is not possible for parents to repeatedly practice the specific subtask of the medical skill they are learning (e.g. changing a gastrostomy button) on their child. The task may be distressing for the child or only need to be done rarely or in emergencies. Yet repeated practice is key for developing expertise (or "muscle memory"). In cases of procedures performed rarely (e.g. emergency tracheostomy changes), simulation is the only practical means of developing the skills required, allowing parents to develop the muscle memory to perform the procedures under stress. Organisations responsible for training families might usefully invest in the equipment necessary for parents to practice the skills repeatedly, or explore getting access to equipment already used for training healthcare professionals. There are some emerging examples of "home-style" simulation suites for training parents and paid carers who care for children with medical complexity in the United Kingdom (https://www.wellchild.org.uk/supporting-you/wellchild-better-home-suite/). There are a few recent studies in the international literature reporting on simulation programmes for training patients and families (Arnold & Diaz, 2016; Barsuk, Wilcox, et al., 2019; Tofil et al., 2013). The success of simulation training in medical education suggests that it ought to be further explored for training family carers.

2.6.2 Metacognition

The principles of metacognition and self-regulated learning are critical to initial skill acquisition and the maintenance of skills over time, as well as for long-term retention of

information. In general, people are not very good at accurately tracking what they know and understand (Dunning, Heath, & Suls, 2004). According to the influential Dunning-Kruger effect, people who are least competent at a skill are the most unaware of their own incompetence (Kruger & Dunning, 1999). Unknown-unknowns can result in people not knowing which questions to ask, being unaware of the risks of a task and not taking into account crucial information when making a decision (Dunning, 2011). Inaccurate self-evaluations of learning have been found to produce poor learning outcomes in experiments (Dunlosky & Rawson, 2012). Techniques to improve the accuracy of metacognitive judgements can improve performance: for example, participants who generated key words to summarise a passage of text performed better in a test (Thiede, Anderson, & Therriault, 2003). The principles of metacognition and self-regulated learning have been widely applied to classroom education (Bjork, Dunlosky, & Kornell, 2013) and to medical education (Colbert et al., 2015). Accurate metacognitive judgements enable you to guide your own learning, so you can focus on areas of weakness or misunderstanding.

2.6.2.1 Implications

Care in the home is done individually and is largely unmonitored. In the case of high-risk activities like providing complex medical care, the unknown-unknowns can be very dangerous: overconfidence can lead to parents not seeking help and potentially harming their child, whilst under-confidence can lead to unnecessary visits to A&E and callouts to community professionals. Training should help parents to have a well-calibrated evaluation of their own skills and performance. It is therefore important that during and after training, parents have their skills reassessed. Healthcare professionals training

families should not rely on self-reported confidence, as confidence can correlate poorly with competence. The least competent people are also likely to be least aware of level of competence (Kruger & Dunning, 1999). Competence should be assessed at regular intervals, especially given that parents are providing care in the home rather than in hospital which can be an isolated environment. This could be done through face-to-face assessment, and potentially through online self-testing with feedback on performance. Parents with accurate metacognitive monitoring will be well-equipped to seek appropriate help and advice from clinicians. Interventions to improve metacognition include videoing yourself and watching the video back, peer review (e.g. by another family member or friend with expertise in the task) and being given feedback on tests (Dunning et al., 2004). Assessing and re-assessing competency might be an important part of training for parents.

2.7 Discussion

In this chapter I have sampled some relevant principles from psychology on how we encode new information and develop new skills. This highlights some possible avenues for applying psychological theory to developing a training package for parents, taking into account the particular strengths and challenges facing this group of highly-motivated non-experts in acquiring clinical expertise to care for their children. In the last section I will explore some reflections on the transfer of psychological theory to the real-world context which I will discuss more in the final chapter of my thesis.

2.8 The transfer of psychological theory to the real-world context

This chapter has described a number of different findings from the psychology literature, and has explored how these ideas might be incorporated into training for parents caring

for medically complex children. A number of papers have sought to do likewise for other real-world contexts such as classroom teaching (Weinstein et al., 2018) and developing and maintaining the professional skills of physicians (Weidman & Baker, 2015). However it is one thing to suggest how psychological theory might be implemented into practice, and another challenge altogether to test and implement this effectively in the real-life context. Effect sizes seen in carefully-controlled lab studies may not generalise to certain real-world contexts (Dunlosky, Bottiroli, & Hartwig, 2009; Goroff, Lewis, Scheel, Scherer, & Tucker, 2018), there may be boundary conditions to effects that limit the effectiveness of transfer (Rowland, 2014; Simons, Shoda, & Lindsay, 2017; Weinstein et al., 2018), and interventions may have unintended consequences in the complexity of real-world situations (Lorenc & Oliver, 2014). We need to conduct applied studies to test how well these effects transfer to the context of training parents to do medical procedures.

There are many design features in the experiments described in this chapter which may affect the generalisability of the findings to the context of training parents (Simons et al., 2017). For example, many of the experimental studies reviewed above use simple experimental materials, control for variables that cannot similarly be controlled in real-life contexts, and use outcomes measures that are quite different to the real-world outcome measures of interest (for example recall of word pairs or word-for-word recall of passages of text). The study material, such as asking participants to study word-pairs that appear for fixed durations on the screen (as is often used in the literature on the testing effect), may be very different to the equivalent study materials in the real world context of training parents to care for medically complex children, where parents study information in leaflets or on websites at their own pace. It may be that effects of retrieval practice, elaborative encoding, and so on are dwarfed by factors in real life contexts such

as motivation levels, the complexity of the study information and metacognitive factors that impact on how long participants choose to the study the information and how carefully. Given this, we cannot assume that well-researched experimental effects can be easily transferred to real-world contexts: we need to test these effects in studies which are representative of the applied context to evaluate their effectiveness.

The relevant effect sizes in lab studies are often the effect size needed to show a statistically significant effect, whereas the effect sizes that matter in applied settings relate to meaningful outcomes (for example in the current context, better training for parents may plausibly lead to fewer complications in children or call-outs to community teams or visits to A&E). In the applied context it is also important to weigh up the benefits relative to the opportunity costs or monetary costs of the intervention. In a large replication study of 100 psychology studies, the magnitude of the effect sizes was half the magnitude of the effect sizes reported in the original papers (Open Science Collaboration, 2015). The reproducibility crisis in psychological science would suggest we ought to be even more cautious about the size of the effects we might find when we try to generalise from experimental findings to applied contexts. In order to find an effect size that is meaningful in a real world context like training parents to do medical procedures, it would seem sensible to combine different factors into an intervention (e.g. the spacing effect, dual-coding and the testing effect), especially given that effect sizes reported in the literature are often inflated due to publication bias. The challenge with combining different techniques, is we will not know which are contributing to any improvements in outcome we find, and it not clear from the literature whether the benefits of the strategies for learning are additive, super-additive or potentially incompatible (Weinstein et al., 2018).

2.9 Conclusions

It is unlikely that psychological theory will be a magic bullet for improving training for parents caring for medically complex children. However, any complex intervention, a training intervention or otherwise, ought to have a coherent theoretical basis (The Medical Research Council, 2019); an understanding of the science of how we learn and develop expertise is important theoretical underpinning for the design of training interventions for parents. Indeed, many of the factors discussed in this chapter have been tested out in the context of training medical professionals. There are of course other important facets to developing a training intervention for parents, including building an understanding the experiences of parents and the clinicians who support these families, and utilising co-production in the design of the intervention. The next four chapters (Chapters 3-6) will help develop an understanding of parents' and clinicians' experiences of the challenges and risks of complex medical care at home. Chapters 7 onwards develops and test interventions for training and supporting parents to do medical procedures at home, utilising psychological theory (as discussed in this chapter) and the findings from the next few clinical studies.

Chapter 3 Enteral tube feeding at home: an analysis of patient safety incidents

3.1 Introduction

As we saw in Chapter 1, many of the types of care that are now common place in the home have significant safety risks that need to better understood. This chapter explores the risks and problems across the system for children with enteral feeding tubes cared for at home, by analysing incident reporting data which is an established method for understanding risks and problems across healthcare systems (Carson-Stevens, 2017; Vincent, 2004, 2007). Incident reporting data is collected routinely across the NHS (other countries globally have similar systems) and is in essence a database of the safety issues reported by healthcare professionals. This chapter presents an analysis of incident reporting data from across the UK for paediatric enteral tube feeding in the community. The following chapter (Chapter 4) uses the same methodology to explore the risks of long term ventilation at home, a less common but higher-risk type of care.

3.1.1 Learning from incidents

Staff across all NHS-funded organisations are encouraged to report any 'patient safety incidents', defined as 'any unintended or unexpected incident that could have or did lead to harm for one or more patients receiving NHS-funded healthcare' (NHS Improvement, 2018). This data is collected by individual healthcare organisations, and then sent to a national repository called the National Reporting and Learning System (NRLS). Analyses of incident reporting data offer a window into the safety of systems, highlighting

vulnerabilities and inadequacies, and detecting common problems and rare and serious risks (Vincent, 2004). It can help identify areas which need further investigation, and where improvements to services are needed (Macrae, 2016). This chapter will therefore provide a broad overview of some of the clinical issues relating to children with feeding tubes cared for at home, and identify priorities for improvement.

3.1.2 The strengths and limitations of incident reporting data

Incident reporting data is useful for providing broad insights into some of the issues across a system and has been used for identifying priorities for improvement across a range of different clinical services and specialties. For example, a recent study generated recommendations from incident reports for improving the safety of out-of-hours palliative care (Williams et al., 2019) and another explored how to improve the safety of care for patients with infusion pumps cared for at home (Lyons & Blandford, 2018). Incident reports provide brief, often ambiguous descriptions of issues for further inquiry or action (Macrae, 2016). They are useful for identifying problems in the processes of care (identifying what happened), but often do not provide much of an understanding of the contributory factors (why it happened). Incident reports can be seen as biased, as they are written from one person's perspective, who only has a partial view of the whole situation (Macrae, 2016). For example, incident reports written by community nurses will detail the nurse's perspective on the situation, but will not allow us to directly explore the perspective of the families who are the main providers of care at home. Although patients and families can report into the national incident reporting system, in practice this is rare. Nonetheless, analysing incident reporting data for children cared for at home will provide a useful background to some of the risks of complex medical care at home:

this methodology is very useful for helping to identify priorities for improvement, which will be addressed later in the thesis.

3.1.3 Counting incidents

The purpose of incident reporting data is for learning about vulnerabilities and inadequacies across a system: it is not there to establish epidemiological trends in safety issues (Macrae, 2016). Incident reporting data is not a reliable source of data for establishing the frequency of a specific type of safety problem (e.g. a misplaced nasogastric tube) or for comparing performance between organisations (Macrae, 2016). Only a tiny fraction of actual incidents are reported, so the data presented in this chapter will only represent the tip of the iceberg and should be viewed as a sample of incidents (Vincent, 2007). Reporting patterns vary between different services, different professions and over time and do not reflect the 'actual number of safety incidents' (Macrae, 2016).

3.1.4 Incident reporting in community settings

Whilst there is a large literature analysing incident reports in the hospital environment, there has been comparatively limited exploration of incidents in the community or home setting (Carson-Stevens, 2017). There are a few recent studies relevant to the current context including an analysis of incidents in primary care for children (Rees et al., 2015) and analyses of incidents in palliative care (Williams et al., 2019; I. Yardley, Yardley, Williams, Carson-Stevens, & Donaldson, 2018). These studies have revealed priorities for improvement. For example, the causes of unsafe palliative care were identified to occur in four main areas: i) errors in medication provision; ii) securing access to timely care; iii) inefficient information processes; and iv) non- medication-related treatment provision (Williams et al., 2019). Interventions recommended by the authors include a unified

record of care for patients nearing end of life (accessible for all professionals and carers involved), and various suggestions for improving the safety and timeliness of medication prescribing at end of life (Williams et al., 2019). CCNs and other staff supporting children with feeding tubes in the community report incidents to their local organisation, which are then sent to the national repository. Analysing these incident reports for children with feeding tubes will provide an overview of the types of problems occurring in the community, and the direct concerns of healthcare professionals during their interactions and home visits with families which will serve as useful background for later chapters in the thesis.

3.1.5 Aim of this study

The aim of this study is to characterize the nature and causes of patient safety incidents involving children with feeding devices at home and to identify priorities for improvement.

3.2 Methods

3.2.1 Data source

The data source for this study is the National Reporting and Learning System (NRLS). This is a national repository of anonymised patient safety incident reports from NHS organisations across England and Wales (NHS Improvement, 2018). Individual organisations and Trusts submit their reports to the national repository. The reports contain open text boxes for information about what happened and why it happened, and categorical information on the patient demographics, level of harm and location and date of the incident. The open text boxes provide a description of the issue which can be analysed to identify what happened (the problems in the process of care), why it

happened (the contributory factors) and the outcome for the patient. Some of this information is detailed, but often it is brief and ambiguous (Macrae, 2016). More information about the NRLS data is available on NHS England and NHS Improvement's website (https://www.england.nhs.uk/patient-safety/monthly-data-patient-safety-incident-reports/)

3.2.2 Sample selection

A sample of incidents relating to gastrostomy, jejunostomy and nasogastric feeding in paediatrics was requested from NRLS for the period 1st August 2012 to 31st July 2017. The following search terms were used to identify the incidents: Gast* button, G-button, mickey button, enteral feed, NGT, NG tube, NG feed, naso-gastric feed, naso-gastric tube, jejunostomy feed, jejunostomy tube, jejunal feed, jejunal tube, gastrostomy. A total of 9327 incidents were received from NRLS.

The incidents were first filtered by location to identify reports at home and then by age to remove incidents involving patients over 18. The remaining 349 incidents were manually reviewed to exclude incidents without a clear description, not relating to enteral feeding, not relating to home care and any remaining reports involving adults. This produced a final sample of 268 incidents for analysis. Figure 3.1 shows a flow diagram illustrating the steps taken to identify the sample.

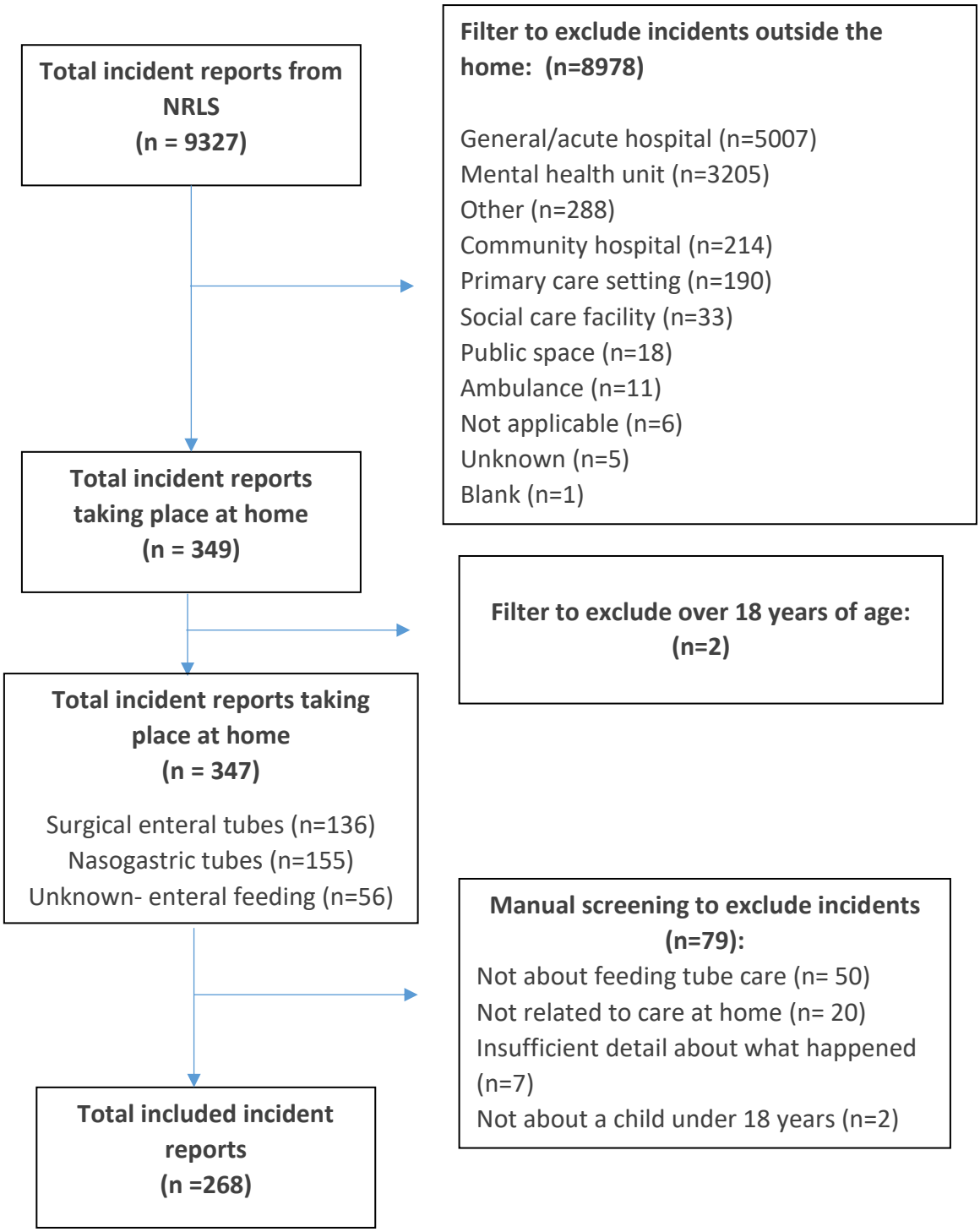


Figure 3.1 Flow diagram showing the steps taken to identify the final sample of incidents for inclusion for enteral feeding

3.2.3 Procedure

The incidents were coded to identify: i) the problems in care (actions or omissions in the process of care, such as inadequate handover or forgetting to do a procedure), ii) the

contributory factors (the conditions in which errors occur and the wider organisational context which might make errors generally more likely, such as inadequate staffing levels or a distressed patient) and iii) the patient outcome (the level of harm to the patient as a result of the incident, such as readmission to hospital or psychological distress) (Carson-Stevens, 2017; Vincent et al., 2000; WHO, 2010). There are a number of frameworks developed and utilised for analysing incident reports based on identifying problems in care, contributory factors and patient outcomes (Carson-Stevens, 2017; Lawton et al., 2012; Vincent et al., 2000; WHO, 2010). For example the Yorkshire Contributory Factors Framework, which was developed empirically through a systematic review of the literature (Lawton et al., 2012), provides a framework for identifying and grouping contributory factors. Many of these existing frameworks have been developed for hospital settings (Lawton et al., 2012; Vincent et al., 2000): some of the categories listed in the frameworks apply the context of home care and some do not. More recently an adapted framework was developed for analysing incidents in primary care which has been used to analyse incident for children in primary care (Carson-Stevens, 2017; Williams et al., 2017). These frameworks were too general in their current form for analysing data on feeding tubes for children cared for at home. As has been done for similar studies looking at specific types of care (I. E. Yardley, Carson-Stevens, & Donaldson, 2018; I. Yardley et al., 2018), I utilised a modified framework approach to adapt existing frameworks for analysing incidents to the context of children with feeding tubes care for at home.

3.2.4 Analysis

The selected incidents were imported into NVivo, version 12. Analysing incidents is a team activity: the incidents were coded primarily by myself (BP) and Rasanat Nawaz (RN),

a Research Assistant, with clinical support from Mr Alex Lee (AL), a paediatric surgeon who performs gastrostomy surgery at the John Radcliffe Hospital in Oxford, and Dr Sarah Haden (SH), a community paediatrician who supports children with feeding tubes outside of hospital. My supervisor Professor Charles Vincent (CV), who has expertise in incident analysis, provided oversight of the development of the coding frameworks. Myself and RN familiarised ourselves with the data and noted relevant themes. We then both coded 10% of the incidents identifying the problems in care, contributory factors and patient outcomes. Initial agreement was over 90%. Discrepancies were resolved through discussion. We then then coded half of the remaining incidents each. Incidents which were unclear were discussed with clinician SH, a community paediatrician, who assisted with the analysis of the clinical circumstances described in these cases. The problems in care, contributory factors and patient outcomes were then grouped into themes and subthemes through an iterative process by adapting existing general incident frameworks to fit the context of enteral feeding in the home (Carson-Stevens et al., 2016; Lawton et al., 2012; Vincent et al., 2000). A sample of 10% of the incidents were coded independently by clinician AL. Agreement was 100% for outcomes and care problems and 95% for contributory factors. CV carried out a final check of the frameworks. Example incidents and coding are shown in Appendix 2. A more detailed description of the analysis process is available in Appendix 3.

3.2.5 Ethics

The incidents from NRLS were anonymised and made available by NHS Improvement through a data sharing agreement with the Oxford Academic Health Science Network (AHSN). This was part of a service improvement project and conducted under the auspices of the Patient Safety Collaborative at Oxford AHSN as part of their regional

Specialised Paediatric Care programme. I was a member of the stakeholder group throughout the duration of this project.

3.3 Results

3.3.1 Problems identified in the processes of care

At least one problem in care was identified in each incident, with some incidents having two or three problems. The problems in care fell into nine different categories (see Table 1). The most common categories were equipment and devices (*n* = 98, 28%), procedures and treatments (*n* = 86, 24%), information, training and support needs of families (*n* = 54, 15%), feeds (*n* = 52, 15%) and discharge from hospital (*n* = 31, 9%). Incidents occurred across the age span, with 32% occurring in children under 1, 26% in children 2-4 years, 27% in 5-11 years and 9% in children 12-17 years (in 6% of incidents the age was unknown). Problems in care are occurring at every stage of the patient journey, and many of them combine and interact.

Table 3.1 shows the specific problems identified within each of the categories. Faulty and damaged equipment was a very common problem (*n* = 62, 18%). It is unclear to what extent the problems with faulty and damaged equipment are underpinned by poor design or by inappropriate use of equipment. Many of the problems highlighted may relate to inadequate training or knowledge of nurses, families and other carers. For example, medications and feeds were administered through the wrong port of a gastrojejunostomy (GJ) tube in 12 incidents. GJ tubes have two ports, one for the stomach and another for the small intestine. Inserting medications or feeds into the wrong port can result in harms such as reflux or vomiting. In two incidents, medication was wrongly inserted into the balloon part of the gastrostomy button device: as a result

the medication would not have been absorbed into the body (the child may have missed critical medication) and could also cause damage to the balloon which could result in the button falling out. If families are not well-trained and supported from the time of their child's surgery, there are likely to be problems later in the community, some of which may lead to considerable harm to the child.

3.3.2 Outcomes for the child

Table 3.2 shows the breakdown of outcomes for each incident. There was a clearly stated harm to the child in 52 (19%) incidents, including 17 (6%) incidents which resulted in a hospital admission or A&E visit. Some of the incidents in the potential harm category may have resulted in harm to the child which was not stated. In some of the incidents classified as 'potential harm' there was a clear potential for harm but no actual harm occurred. An example of this would be where a child was fed through an NG tube despite being unable to obtain aspirate and a suitable pH value. While we cannot say how often these incidents occur in a given population of children it is clear that there is potential for significant harm to occur while children are being cared for at home.

3.3.3 Factors contributing to the incidents

There were 97 contributory factors identified in the incidents. In the majority of incidents, no contributory factors were mentioned, reflecting the relatively brief narratives in the reporting system. Contributory factors fell into five broad categories: organisational factors (32%, *n* = 31), staff factors (21%, *n* = 20), family carer factors (20%, *n* = 19), feeds, equipment and medication factors (12%, *n* = 12) and patient factors (15%, *n* = 15). Table 3.3 gives definitions and example quotes for each category. Organisational factors such as poor communication between services, lack of service availability and

evening and weekend discharges were common. These factors highlight the transition from hospital to home as a particularly risky period and concerns regarding the availability of community services to support families. The circumstances of the family carer, such as the involvement of secondary family carer (e.g. grandparent), ongoing child protection issues or a parent experiencing distress, all affected the provision of care. The training needs of individual staff members was also a common problem and raises questions about the safety of care in the community in some services.

Table 3.1 Problems in the process of care (enteral feeding)

PROBLEMS IN CARE	**N**
Administration and documentation	**7**
Errors in documentation	4
Documentation not available	3
Communication	**7**
Communication failures between staff	3
Inadequate handovers in the community	3
Communication problems between staff and family	1
Discharge	**31**
Inadequate or no handover from hospital to community teams	13
Required equipment, medication or feeds not supplied at discharge	9
Other discharge problems	6
Lack of support in the community post-discharge	3
Equipment and devices	**98**
Faulty or damaged gastrostomy and jejunostomy devices	25
Faulty or damaged feeding equipment (e.g. giving sets, pumps)	24
Faulty or damaged nasogastric tubes	13
Equipment not available	13
Incorrect equipment ordered or delivered	7

Device is leaking or loose	6
Equipment not delivered or delayed	4
Equipment used incorrectly	4
Equipment out of date	2
Feeds	**52**
Feed not given on time	12
Incorrect feed or feeding regime given	12
Incorrect feed ordered or delivered	9
Feed given through incorrect port	8
Feed not delivered or delayed	4
Out of date feed delivered or administered	3
Child left unattended during overnight feeding	3
Feed leaking	1
Information, training and support needs of families	**54**
Family carer has not received appropriate training or information	28
Family carer does not follow procedure correctly or goes against advice	16
Family carer given inappropriate advice	5
Lack of support for family in the community	3
Family carer given conflicting information	2
Medications	**16**
Medication administered through incorrect port	4
Medication inserted into balloon	2
Medication not given	2
Medication or prescription errors	2
Wrong dose given	2
Difficulties obtaining medication	1
Medication blocks tube	1
Medication given at wrong time	1
Wrong medication given	1
Procedures and treatment	**86**

Gastrostomy button or jejunostomy device comes out	11
Delays to procedure or no staff available	11
Problems or complications passing nasogastric tube	11
Tube wrapped around neck during overnight feed	6
Wrong length nasogastric tube passed	6
Wrong size button fitted	6
Procedure not followed correctly	6
Problems changing or fitting button	5
Feed, water or medication put down tube without confirming position	5
Complications relating to gastrostomy site	3
Damage from nasal bridle	3
Staff member does not have appropriate training	3
Silver nitrate related problems	3
Nasogastric tube comes out	2
Child pulls out feeding tube during overnight feeding	1
Inappropriate treatment	1
Procedure done on wrong patient	1
Other	**2**
Missed appointments or reviews	2

Table 3.2 Outcomes for the child (enteral feeding)

OUTCOMES	**N**
Clearly stated harm to child	**52**
Hospital admission or A&E	17
Skin damage, pain or distress relating to gastrostomy site	12
Diarrhoea, sickness or abdominal pain	7
Feeding tube wrapped around neck	6

Skin damage from nasal bridle	3
Child not fed	2
Pain or distress passing NG tube	2
Child aspirating blood	1
Seizure	1
Hypoglycaemia	1
Potential for harm (or harm not stated)	**216**

Table 3.3 Types and frequencies of contributory factors with illustrative quotes (enteral feeding)

Contributory factors	N	Illustrative quotes
Family carer factors: features of the family carer or their circumstances that make caring for the child more difficult, or may contribute to problems in care.	**19**	**Secondary family carers:** *"The child is in the care of the grandma on a Tuesday and Thursday… the Mum had been trained… and was signed her off as competent, but not the grandmother. It seems that she [the Grandma] didn't want to disturb her daughter so she did it [reinserted the NG tube] herself."* **Child protection issues:** "*This family have already had a faulty button which has been sent for analysis and reported to have a tear in the balloon in an abnormal place. Cause unknown. This family have previously been subject to child protection issues due to inappropriate use of equipment."*
Patient factors: features of a patient that make caring for them more difficult and therefore more prone to error.	**15**	**Child distressed during the procedure***: "Child very upset about the procedure [changing a button] screaming and protesting… checked as the fit of the button looked tight… spare 3cm, in situ 2 cms… she [Mum] acknowledged she had handed me an old button by mistake because of all the upset."* **Complex medical history:** ***"****Attempting to pass [nasogastric] tube as per protocol to right nostril but unable to advance past 14-15cm felt may be a blockage, patient limp, loss of colour and unresponsive… Since his discharge home from hospital following his birth the child has had several admissions to hospital. These have been with upper respiratory tract*

		infections and vomiting and had a snotty nose and cold at the time of the incident."
Staff factors: features of individual staff members that may contribute in some way to problems in care.	**20**	**Lack of knowledge and preparation: "***When the parent asked her [the nurse] to carry out care of the Freka tube this was something that she had not had time to prepare for in advance and instead of taking time to read through the care plan to clarify what was needed she went ahead and dealt with what she thought was the correct procedure."* **Variability in best practice guidance from consultants:** *"The water in the balloon was changed within a week of insertion [of gastrostomy], the best practice guidance is 3 weeks post insertion. No guidance given from the ward on referral or to patient. The practice of inserting pegs or buttons can vary from individual consultants and changing devices. Practitioners unaware of new practice."*
Organisational factors: features of the way organisations function which affect the provision of care available.	**31**	**Staff/service availability: "***Visited family home to pass a routine monthly NGT [nasogastric tube]... Throughout initial discussions on when NGT was last place, mum disclosed that she had called the CCN [community children's nursing] team on [date]. Unfortunately we were not available to attend and mum advised she did not want to go all the way to the hospital and wait for ages, so she passed it herself."* **Evening and weekend discharges:** *"Patient discharged from hospital with Nasogastric tube and feeds, risk assessment not completed properly, risks identified with high PH not highlighted. Parent competency not complete. Community children's nursing team received referral form post discharge of patient at 17.20pm in evening (outside working hours)."* **Poor communication between hospital and community:** "*Unable to find any information on a patient's Trans Gastric Jejunal tube… The nurse needs to know the size of the tubes in order for extension tubes to be sent out to the home on a regular basis. The team have experienced a frequency of similar incidences and generally poor communication with our Teams resulting in families not able to change water in the balloon."*

Design and supply of feeds, equipment and medication factors: factors relating to the design of equipment, feeds and medications which affect the provision of care.	**12**	**Similar names of feeds:** "*Care required when adding enteral feeds to the ordering system, paying particular attention to the names of feeds as many names are very similar."* **Design of equipment:** *"Since the introduction on the new ENFITT connectors provided in the giving set, the connection onto the Mic key button extension is not as secure and therefore the milk feed is leaking."* **Design and durability of equipment:** *"The device has an increased risk of leaking if the feed is high in MCT oil or amino acid content which is applicable to the paediatric caseload. They [the feeding company] have advised that some breaks are the results of stress fractures and patients and carers should be encouraged not to turn it too tight."*

3.4 Discussion

3.4.1 Summary

This analysis of incident reports on enteral tube feeding at home has identified a number of safety concerns across the system. Commonly reported problems included faulty and broken equipment and family members not receiving sufficient training or information. Underlying causes included organisational factors and factors relating to staff and family carers. Incident data underestimates the scale of harm so this data represents only a small proportion of the total problems occurring in the community (Vincent, 2007). This study highlights a range of safety concerns which require further investigation and action.

3.4.2 Training of family carers

Inadequate training of family carers was a frequently reported concern. Other studies have found evidence of safety concerns in the practices of some family carers (Evans et al., 2006, 2012, 2010). Families have also reported concerns about making mistakes and feeling inadequately prepared (McDonald et al., 2016; Spiers & Beresford, 2017). The

adequacy of training and information for parents needs to be viewed as a system issue and vital to the safety of care at home (McDonald, McKinlay, Keeling, & Levack, 2017).

3.4.3 Equipment and devices

Incidents relating to broken or faulty equipment and the availability of equipment were common, and have also been reported in palliative care settings elsewhere (I. Yardley et al., 2018). The cause of faulty or broken equipment is likely to be a mixture of issues in product design and misuse of equipment by parents and staff, and is therefore partly a training problem. Different surgical/gastroenterological specialists and feeding healthcare professionals use different devices, which creates a complex landscape for parents and community services to navigate. Problems with reliability of equipment and provision of back-up equipment is resulting in children missing vital feeds (i.e. going without food) and medications.

3.4.4 Provision of services in the community

Underlying a number of the problems identified, particularly in the 'procedures and treatments' section, is inadequate provision of services in the community to support families. Lack of expertise and availability of services for specialised paediatric care have been identified by others previously, including parents (Kirk & Glendinning, 2004; Whiting, 2019). This study indicates that there are varying levels of expertise amongst those who provide care, whether that be parents, Community Children's Nurses (CCNs), paid carers or school or respite staff. There are clearly issues around training for staff as well as parents.

3.4.5 Discharge from hospital

The weeks following discharge from hospital are a high-risk period. We found a number of instances where community teams had not been informed of the child's discharge, and cases where children were discharged without the required equipment, medication or feeds. There are clearly some problems with continuity of care between hospital and community services. Pressure to discharge patients due to bed shortages may be increasing the risks. Better preparation and support for parents, and more co-ordination between community and hospital services could help address some of the problems identified at discharge. It can be tempting to think the problems identified in the incidents are mostly related to the transition from hospital and home, but the ranges of ages of the children involved suggests there are also considerable problems in long-term care.

3.4.6 Strengths and limitations

Incident reports are excellent tools for learning and for generating improvements to current systems. Patient safety incidents have been extensively studied in the hospital setting, but to date there has been limited research in other care settings (Carson-Stevens et al., 2016; I. Yardley et al., 2018). This study is, to our knowledge, the first to examine incidents relating to the safety of enteral feeding at home. It identifies a range of problems that need further inquiry and collective action (Macrae, 2016). More broadly, this study begins to examine a new area of research in the field of patient safety: care in the home and the involvement of family members in providing this care (Institute for Healthcare Improvement, 2018).

The limitations of incident reporting have been discussed in the introduction of the chapter, and in detail elsewhere (Macrae, 2016). Incident reporting generally only detects a small proportion of the total number of adverse events occurring (Vincent, 2007). Our study therefore cannot comment on the frequency of safety problems with enteral feeding devices at home. We note that the terms 'PEG' and 'PEJ' were not included in the search terms so it is possible some relevant incidents were missed. These reports are almost exclusively provided by healthcare professionals and, as a result, our study cannot adequately explore the perspective of parents. Ideally, families should be involved in incident reporting as they are the primary caregivers. Future studies should examine parents' safety concerns and compare the findings with the themes identified in this study. Previous studies have found that families and patients are able to identify factors which contribute to safety incidents and that these are sometimes different from those identified by healthcare professionals (Hernan et al., 2015).

3.5 Conclusions

This chapter has identified a range of safety problems occurring with enteral tube feeding at home, and given insight into problems and vulnerabilities across the whole system from the perspective of healthcare professionals who support families at home. The need to ensure consistently good quality training for family carers was clear from the data, as well as other emerging issues around training for staff, availability and reliability of equipment and the vulnerability of the period immediately following discharge from hospital. Later chapters will explore the perspective of families directly, to complement the clinical perspectives gained from incident reports. The next chapter will now look at incident reporting data for children on long-term ventilation, a higher-risk type of care.

Chapter 4 Long term ventilation: An analysis of patient safety incidents in the community

4.1 Introduction

4.1.1 Long-term ventilation

This chapter uses the same methodology as the previous chapter to analyse patient safety incidents relating to children on long-term ventilation at home. Long term ventilation is a mechanical aid for breathing, used either invasively by tracheostomy or non-invasively via a mask interface for all or part of the 24 hour day (Wallis et al., 2011). Long term ventilation is less common than enteral tube feeding, but much more high risk, as we saw in Chapter 1. There are increasing numbers of long-term ventilated children and young people living at home, with a wide variety of underlying conditions (Brookes, 2019). Children on long-term ventilation often need an extensive care package to provide long term medical, nursing, and physiotherapy support (Wise et al., 2011). Some children need to be constantly monitored during the day and night: this would typically be done by parents and paid carers as part of a care package. Common procedures carried out by parents and staff include changing tracheostomy tapes, suctioning of the tracheostomy, manual ventilation, ventilator care, infection control, stoma care and emergency planning (Amin et al., 2017). Parents caring for children on long-term ventilation face major challenges due the intensity and complexity of the care (Falkson, Knecht, Hellmers, & Metzing, 2017).

By examining incidents for children on long-term ventilation as well as enteral feeding, I will be able to explore how specific the problems identified in the previous chapter are to enteral feeding or whether they are risks of home care more generally. Although later

sections of my thesis focus on gastrostomy care, the wider aim of my thesis is to explore the training and support needs of parents caring for medically complex children more generally at home. There is more potential for serious harm to occur for children on long-term ventilation compared to children with gastrostomies. Emergency situation are likely to be more common for long-term ventilation. This type of care might serve as a useful example for understanding the characteristics of emergencies in home care more generally. Many children on long-term ventilation also have other medical devices, such as gastrostomies, so some of these incidents in this chapter and the previous chapter will be occurring in the same population of children.

4.1.2 Aim of study

The aim of this study is to describe the nature and causes of reported patient safety incidents relating to care in the community for children on long-term ventilation.

4.2 Methods

4.2.1 Data source

The data for this study comes from the National Reporting and Learning System (NRLS). More details about NRLS data are given in the previous chapter.

4.2.2 Sample selection

A request for all incidents relating to long-term ventilation was sent to NRLS for incidents occurring between January 2013 and December 2017, for patients under 18 years of age. The following search terms were used to identify the incidents: Long term vent*, long term ventilation, home vent*, level 3 vent*, level three vent*, lvl 3 vent*, lvl three vent*, trache, trachy, and trachi* - where the asterisk is a 'wildcard' representing one or more other characters. A total of n = 4036 incidents were received from NRLS.

The incidents were filtered by reported incident location to identify incidents reported in the community. They were then manually screened to remove any further incidents not relevant to ventilator or tracheostomy care, or not occurring in community settings. This produced a final sample of 217 incidents for analysis. Figure 4.1 shows a flow diagram illustrating the steps taken to identify the sample.

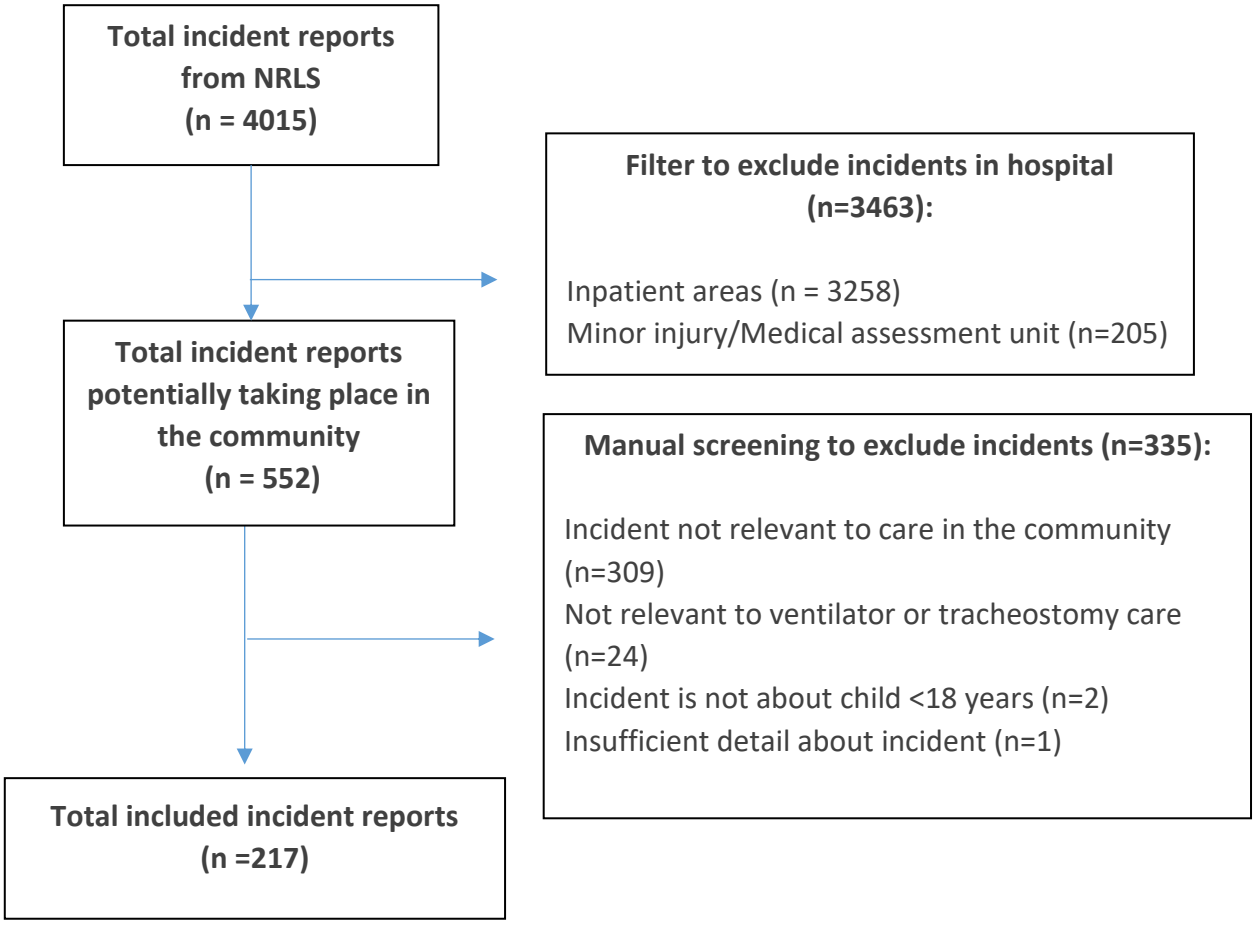


Figure 4.1 Flow diagram showing the steps taken to identify the final sample of incidents for review for long-term ventilation

4.2.3 Procedure

As in the previous chapter, the free text boxes for each incident were coded to identify the reported problems in care, any stated contributory factors and any stated patient outcome where evident from the reporter's narrative. This is an established procedure

for analysing incident reports in the literature (Carson-Stevens et al., 2016; Vincent et al., 2000; I. E. Yardley, Carson-Stevens, & Donaldson, 2018). An adapted framework approach was used, as in previous studies (Yardley, Yardley, Williams, Carson-Stevens, & Donaldson, 2018). An initial framework was created for problems in care, contributory factors and patient outcomes based on the framework developed in the previous chapter for enteral tube feeding. This framework needed some further adaptions to fit the context of long-term ventilation: although the broad headings did not need much adapting, the individual subthemes needed revising to fit the context of long-term ventilation. As with the previous study, the coding was conducted by myself and a research assistant, with support from a clinician with expertise in long-term ventilation and my supervisor who has expertise in incident analysis.

4.2.4 Analysis

The selected incidents were imported into NVivo, version 12, software for qualitative analysis. Myself and a research assistant first independently coded 30 of the incidents identifying the problems in care, any stated contributory factors and any stated patient outcome. The frameworks were then adapted through an iterative process based on the initial coding. We then coded a further 50 incidents independently. Agreement between the researchers was good (>95%). Discrepancies in coding were resolved through discussion. We then coded half of the remaining incidents each. Clinical guidance from Emily Harrop (EH), a paediatrician who supports children on long term ventilation, was sought when needed. A sample of 10% of the incidents were coded independently by EH. Agreement was >90% for the outcomes and care problems and >90% for the contributory factors.

4.2.5 Ethics

The NRLS data were acquired from the Patient Safety Team at NHS England and NHS Improvement, and made available through a data sharing agreement between Oxford Academic Health Science Network (AHSN) and NHS England and NHS Improvement. This service improvement project was a part of the regional Specialist Paediatric Care programme at the Oxford Patient Safety Collaborative at the AHSN which I was a member of.

4.3 Results

4.3.1 Age breakdown

Incidents were reported across the age span, with 1% reported in babies under 28 days, 22% in children from 1 month to 1 year, 26% in children from 2 to 4 years, 28% in children from 5 to 11 years and 17% in children from 12 to 17 years. In 5% of incidents the age was unknown.

4.3.2 Problems identified in the processes of care

At least one problem in care was identified in each incident, with some incidents having two or three problems. Table 4.1 shows the specific problems identified within each of the categories. The most common problems in the processes of care were issues with faulty equipment and availability of equipment (*n* = 97), factors relating to procedures and treatment (*n* = 92) and concerns around staff availability and competency (*n* = 27). Some of the problems listed under procedures and treatments highlight potential concerns around staff competency (e.g. wrong size tracheostomy tube fitted or protocol not followed correctly). This is in addition to 12 incidents in which parents raise concerns about staff competency. There were also 18 instances of problems related to

communication and 16 relating to the information, support and training needs of families. Some of these reported incidents did not describe safety incidents as such but general concerns, such as parents concerned about staff competency or staff concerns about a child's or parent's behaviour.

4.3.3 Outcomes for the child

There was clearly stated harm to the child in 87 (40%) incidents, as identified in the free text descriptions. Table 4.2 shows the breakdown of outcomes for each incident. Common outcomes resulting in harm to the child included CPR required, emergency tracheostomy change in community setting, and substantial child and parent distress. Some of the incidents in the potential harm category may have resulted in harm to the child which was not stated in the free text. In some of the incidents classified as 'potential harm' there was indeed a clear potential for harm, but no actual harm occurred. An example of this would be where the child had the wrong size tracheostomy tube fitted.

4.3.4 Factors contributing to the incident

There were 50 contributory factors identified in the free text descriptions of the incidents. In the majority of incidents, no contributory factors were mentioned by the reporter, reflecting the relatively brief narratives in the reporting system. Contributory factors fell into six broad categories: family carer factors, equipment factors, organisational factors, patient factors, staff performance factors and environmental factors. Table 4.3 gives definitions and example quotes for each category. These factors highlight the need for careful assessments and management of risk. Significant risks include challenging behaviour and distress experienced by children, staff shortages and

out of hours care. Contributory factors relating to equipment highlight potential improvement to design, packaging and instructions.

Table 4.1 Problems in the process of care (long-term ventilation)

PROBLEMS IN CARE	**N**
Administration and documentation	**3**
Notes or documentation errors	2
Notes or documentation not available	1
Communication	**18**
Communication failures between staff	9
Communication or handover problems between staff and family	4
Disagreement between staff and family	5
Discharge	**4**
Inadequate or no handover from hospital to community teams	2
Required equipment not supplied at discharge	1
Unsafe discharge	1
Equipment and devices	**97**
Incorrect equipment ordered or delivered	10
Equipment not available	9
Equipment delayed or not delivered	4
No back up equipment available	6
Emergency tracheostomy bag not with child	4
Problem with ventilator circuit	7
Faulty or damaged equipment:	**52**
Suction machine	14
Tracheostomy tube	8
Tapes	8
Humidifier	6
Plastic cuff on tracheostomy device	4
Alarm does not sound when it should have	4

Ventilator	4
Circuit	2
Oxygen saturation monitor	2
Information, training and support needs of families	**16**
Family carer has not received appropriate training or information	5
Family carer does not follow procedure correctly or goes against advice	4
Concerns relating to family carer's actions	3
Family carer given inappropriate advice	1
Lack of support for family in the community	1
Child looked after by teenage sibling	1
No training for secondary carers or refresher training for primary carers	1
Medications	**8**
Medication or prescription errors e.g. dose errors, missed medication	7
Medication unavailable	1
Procedures and treatment	**92**
Tracheostomy tube come out or is dislodged	21
Protocol not followed correctly	15
Wrong size tracheostomy tube fitted	12
Issues with tracheostomy tapes (too loose/tight, wet or skin damage)	10
Water gets in or nearly gets into tracheostomy	9
Child deteriorating	6
Child gets cut when removing tracheostomy tapes	3
Tracheostomy tube is blocked	3
Problems relating to tracheostomy	3
Wrong ventilator settings	1
Child suctioned at wrong length	1
Child desaturates while being cared for by healthcare assistants	1
Child unable to summon help when needing suctioning	1

Spare tracheostomy tube not clean	1
Inappropriate action by nurse following drop in oxygen saturations	1
Too much water inserted into tracheostomy cuff	1
Forgetting to turn the ventilation on	1
Oxygen cylinder is empty	1
Parents refuse specialist care support	1
Staffing problems	**27**
Parents concerned about staff competency	12
Staff asleep whilst caring for child	9
No staff available	6
Staff do not follow up problem with family	2
Staff training concerns	2
Child behaviour	**8**
Child interfering with equipment or care – query self-harm	6
Child abusive to parents or staff	2
Parent behaviour	**2**
Parents aggressive to staff	1
Missed appointment or reviews	1
Other	4
Transport problems	4

Table 4.2 Outcomes for the child (long-term ventilation)

OUTCOMES	N
Clearly stated harm to child	**87**
Emergency or unplanned tracheostomy change	35
Child severely distressed or in pain	16
Hospital admission or ambulance called	10
Skin damage	8
Distress to parents	6
Child desaturating	4
Other	4
Child may be moribund	2
CPR required	2
Potential for harm (or harm not stated)	**131**

Table 4.3 Types and frequencies of contributory factors with illustrative quotes (long-term ventilation)

Contributory factors	N	Illustrative quotes from incidents
Family carer factors: These are features of the family carer or their circumstances that make caring for the child more difficult, or may contribute to problems in care.	**4**	**Safeguarding concerns:** **"**Report received from the mother of a child who receives continuing care support that the child had been sleeping on an inappropriate piece of equipment. The child is at high risk of developing pressure sores and has been sleeping on a blow up lilo. He is completely immobile and tracheostomy and oxygen dependant […] There are ongoing child protection concerns which necessitate the requirement for dad's continued input into the child's care." "A long term ventilated child via a tracheostomy was taken to school without his emergency tracheostomy bag. Sometimes it is a rush to get out in the morning and this may have been a contributing factor."

Patient factors: Features of a patient that make caring for them more difficult and therefore more prone to error.	**10**	**Communication challenges** **Complex needs:** *"*Community patient who is quadriplegic and is ventilated via tracheostomy was unable to summon help when airway needed clearing while he was at home in bed. He has very limited verbal communication which is worse if airway compromised" **Child distressed:** "known risk child will de-cannulate when anxious or displaying behaviours. At 15:15 child was tired and upset and pulled her tracheostomy out."
Staff performance factors: Features of individual staff members that may contribute in some way to problems in care.	**10**	**Staff panic whilst changing tracheostomy:** "Child needed to have tracheostomy tapes changed. Staff liaised about who was going to hold the tracheostomy and who was going to change the tapes. Staff member 2 decided agreed to hold the tube in place whilst staff member 1 changed the tapes. Whilst the tapes were being changed, child proceeded to vomit. As staff member 1 sat child up, staff member 2 let go of the tracheostomy and staff member 1 stated that the tracheostomy tube nearly fell out. Staff member 1 stated that she had shouted at staff member 2, with staff member 2 stating that she had panicked."
Organisational factors: These are features of the way organisations function which affect the provision of care available.	**12**	**Weekends and out of hours:** "Phone call received from LTV [long term ventilation] patient whose humidifier had failed out of hours. As per protocol the parent had called the local hospital where a spare was kept but they were unable to find it." **Staffing pressures:** "A 24 hour ventilator dependent tracheostomy child was discharged home following a very prolonged hospital admission. Child under care of children's long term ventilation team. Standard of care is that every trache [tracheostomy] long term vent [ventilation] patient is visited within 24 hours of discharge to follow up patient and ensure no issues have arisen and troubleshoot any problems. Due to nurse vacancy within the service and only part time physio within the service the service was unable to offer a home visit until days later."
Equipment factors: These are factors relating to the design of	**12**	**Factors relating to manufacturing or suppliers** **Issues with packaging:** "Prior to changing trachy tube I noted that the tube I was planning to insert was a different length to the tube I was

equipment which affect the provision of care.		replacing. The other tube was correct length. The details are very similar on both boxes, which look very similar." **Crucial information missing from equipment instructions:** "Equipment supplied from manufacturers did not have the cleaning instructions in place, if the filters became wet the device would not work."
Environmental factors: Features of the environment that may contribute to problems in care.	**2**	**Child is on a plane: "**Child who has long term ventilation was on a flight back from holiday and required ventilation. The portable ventilator failed after 15 minutes and the child had to be woken up and kept awake so she could breathe unaided." **Child is in a swimming pool:** "Patient attending pool session at school. Became unwell in the water so removed from the pool by school staff with LTV staff on poolside."

4.4 Discussion

4.4.1 Summary

There are significant risks that need to be managed when caring for children on long-term ventilation in the community. This analysis of patient safety incident reports found some serious safety concerns, with 40% of incidents leading to a clearly stated harm to the child, this included cases of potential death, the need for CPR and hospital admissions. When things do go wrong in the context of long-term ventilation, the consequences for the child and family are often very serious. Common problems identified across the system included faulty and broken equipment, gaps in knowledge and training of staff, and substantial pressure and anxiety experienced by parents. Some of these are very similar to the problems identified for children with enteral feeding tubes identified in the previous chapter, and are likely to be risks across home care more generally. If children with complex care needs are to be cared for safely at home, the provision of services to support these families need to be improved in several areas.

4.4.2 Improving knowledge and training for staff and carers

A variety of carers look after these children including family members, nurses, paid carers, school and nursery staff and respite staff. High-risk emergencies can happen at any time, such as blocked or dislodged tracheostomy tubes or ventilator malfunction. Some of the incidents in our study highlight lack of training for staff supporting children on long-term ventilation, including staff panicking in emergency situations. The importance of good quality training and ongoing monitoring of skills for all staff that support these children is paramount for such high-risk care. Simulation training could be more widely used for ensuring staff, parents and other carers can safely manage emergencies (Motola et al., 2013).

4.4.3 Maintenance and availability of equipment

Children on long term ventilation are vulnerable not only to the actions of inadequately trained staff but also to machine failure (Wise et al., 2011). Many incidents in our study were related to faulty or broken equipment which may partly be due to design issues with the equipment, but could also be a result of misuse of equipment by staff or families. In some incidents parents did not have the backup equipment required to perform unplanned tracheostomy changes, leaving the child at risk. There were also instances where information on the packaging did not match the item, as well as similar packaging for different items, leading to incorrect equipment being delivered and used. Problems with the supplies of vital equipment is very stressful for families (Carter et al., 2012).

4.4.4 Improving care packages and support for parents

Many parents reported concerns with staff skills or paid carers falling asleep while caring for their child. Other parents reported having to cover multiple night shifts due to staff shortages, whilst also caring for their child during the day. The data highlights the need to improve training for paid carers and potential problems arising from parents and staff providing care when they are tired or sleep-deprived. Parents need to be able to hand over responsibility of care to staff without anxiety.

4.4.5 Coordination of support services

It has been suggested that developments in appropriate community-based services have not kept pace with the medical and technological advances that now allow children with complex needs to be discharged (Kirk & Glendinning, 2004). Our data highlights ongoing problems with the co-ordination of care (Kirk & Glendinning, 2004). It is the responsibility of commissioners and providers of care to have high quality systems in place to train and support all those providing such high-risk care.

4.4.6 Strengths and limitations

Analysing incident reporting data for children on long-term ventilation has provided a broad overview of the risks across the system, identifying priorities for further inquiry and collective action (Macrae, 2016). This chapter has identified some serious concerns in the care of children on long-term ventilation, with a number of children coming to serious harm which could have been avoided. One of the clear priorities from this chapter and the previous chapter is improving training and support for families, as well as training for other staff and carers in the community.

The reported narratives in the incident data are often incomplete, with some reporting general concerns, other clear problems in the processes of care, and a minority identifying clear contributory factors or underlying causes. Incident reports do not provide a complete picture of what happened and why (Macrae, 2016). The data also cannot be used to estimate the scale of harm: it represents only a small proportion of the total problems occurring in the community, underestimating the scale of harm (Sari, Sheldon, Cracknell, & Turnbull, 2007; Vincent, 2007). NRLS incidents are predominantly reported through NHS systems meaning third sector respite care settings, special schools and private agency staff may not be covered directly under the NRLS data repository. Many of the incidents describing parental concerns are reported through nurses and other healthcare professionals. A next important step is to better understand the concerns of families directly from parents themselves. Learning directly from the experiences of families is the focus of the following two chapters (Chapters 5 and 6).

4.5 Conclusions

This study identifies a range of safety concerns for children on long term ventilation. Long term ventilation is a very high risk type of care, which is becoming increasingly common (McDougall et al., 2013). A national report from 2020 identifying 3061 children and young people on long term ventilation, which the authors advise is an underestimate (The National Confidential Enquiry into Patient Outcome and Death, 2020). Key areas of concern identified from the incident reporting data presented in this chapter are the training of staff and families who support these children in the community, the reliability and availability of equipment, the significant stress placed on families and the co-ordination of services. It is important to note that these incidents likely represent the tip of the iceberg. The high-risk nature of the care means that consistently high-quality

training for families and for staff is needed. The support needs of families were more evident in the data on long-term ventilation as well as training for staff and paid carers, whereas issue pertaining to training for parents seemed to be more prevalent in the previous chapter on tube feeding.

Analysing incident reporting data for two different types of care carried out at home has provided some insights into the risks and common problems across the system for children with complex medical needs cared for at home. Training and support for families is one issue that emerges from the data in both contexts as a key area for improvement. Incident reports are written mostly by healthcare professionals, and tell us little about the direct experiences of families. The next two chapters (Chapters 5 and 6) present analyses of interview and survey data with families, to enable a better understanding of the experiences of families caring for medically complex children and their training and support needs.

Chapter 5 An analysis of interviews with parents on the challenges of caring for children who require complex medical care at home

5.1 Introduction

This chapter presents a thematic analysis of interviews with parents on the challenges of caring for children who need complex medical care at home. The previous two chapters have explored the safety concerns of healthcare professionals who support children with feeding tubes and long-term ventilation. These next two chapters explore the direct experiences of parents, with a view to informing the development of a package of training and support later in my thesis. This chapter describes the experiences of parents who perform complex medical procedures for their children at home; the chapter explores the responsibilities of parents (including their experiences of performing medical procedures for their children), the impact on daily life (such as the challenges of going out) and the parents' journey over time (including the development of expertise).

5.1.1 Understanding the experiences of families

In this chapter I explore the experiences of families who do complex medical procedures for their children in more detail, with a view to informing the development of a training and support package later in my thesis. In the first chapter of my thesis I explored some of the literature on the experiences of parents caring for medically complex children at home: it was clear from this literature that the burden of care placed on families is substantial (Berry et al., 2013; Kuo, 2011; Lee & Lynn, 2017). Burden of treatment theory was originally developed to describe the work of patients with chronic conditions (and their caregivers) who are increasingly delegated tasks previously undertaken by the healthcare system, such as self-monitoring, drug management and passing information

between healthcare professionals (Mair & May, 2014; May et al., 2014; May, Montori, & Mair, 2009). Burden of treatment theory is a useful lens for exploring the challenges faced by parents who carry out complex medical procedures for their children. The parenting of children with complex medical needs is similarly complex and burdensome, and has been described in one study as 'intense parenting' (Woodgate, Edwards, Ripat, Borton, & Rempel, 2015). Burden of treatment theory explores the shift in accountability whereby traditional healthcare tasks, such as performing medical procedures, are delegated to families. It also explores individual differences in families' capacity to undertake this work and describes the skills families need to be successful. Burden of treatment theory is therefore utilised in the discussion section as a lens for interpreting the results, and exploring the many responsibilities that are placed on parents caring for medically complex children, and the factors which make managing the burden of care easier or more challenging.

5.1.2 Aim of study

The aim of this qualitative study was to explore the challenges faced by families caring for children who need complex medical care at home. I present a secondary analysis of 11 in-depth interviews with parents whose children had abdominal surgery, and needed ongoing medical procedures at home. A better understanding of the challenges experiences by these families will inform the development of the training package later in the thesis.

5.2 Methods

5.2.1 Sample

5.2.1.1 The original study from which my participants were selected

This chapter presents a secondary analysis of interviews with parents from a previous study conducted as part of the 'The Database of Personal Experiences of Health and Illness' (DIPEx) project led by the Department of Primary Care at the University of Oxford (Herxheimer & Ziebland, 2008; Hinton, Locock, Long, & Knight, 2018). The original study consisted of 44 in-depth interviews with parents from the United Kingdom whose child had abdominal surgery in the first year of life (Hinton et al., 2018). Extracts from the interviews are available publicly on the Healthtalk.org website (DIPEx, 2019).

In the interviews, parents talked about a broad range of issues including diagnosis, birth planning, the abdominal surgery itself and life back home. To capture the long-term impact of this surgery, the original sample included a broad range of ages of the children at the time of interview. Interviews lasted between 1 hour 15 and 3 hours 30 minutes. Further information about the recruitment and participants are available in the original publication and online (DIPEx, 2019; Hinton et al., 2018). The interviews began with unstructured narrative prompted by an open-ended question and were followed up by a semi-structured section following up on issues raised by parents and themes suggested by the literature and advisory panel. The open narrative approach to the interviews lends itself to supra analysis, i.e. secondary analysis of an existing dataset to investigate a different question to that of the primary research (Heaton, 2004). Although the original study was designed to explore parents' experiences of having a baby who needed abdominal surgery, a significant proportion of the participants talked extensively about

the long-term impact of caring for their children at home, which has not yet been explored in publications from this dataset (Hinton & Armstrong, 2020; Hinton et al., 2018).

5.2.1.2 Sample included in this study

For this chapter, I selected a purposive sample of participants from the original study to include families who provided complex medical care for their child at home. I included all participants from the original study who described performing specialist medical procedures for the children; this included procedures such as tracheostomy care, feeding tubes, stomas and bowel washouts. A total of 11 relevant interviews were identified and full transcripts accessed through a data sharing agreement. All parents had given informed consent before taking part and consented for their data to be used in publications, stored in an archive, and available (subject to approval) to other researchers for secondary analysis. The original study was approved by Berkshire Ethics Committee, reference 09/H0505/66.

Table 5.1 shows information about the 11 families included in the analyses presented in this chapter. All infants had surgery in their first year of life, with their age at time of interview ranging from 18 weeks to 9 years (see Table 5.1). Some of the children remained in hospital following birth for long periods of time, including one child who was in hospital for 3 years before going home. Other children were discharged home shortly after birth and returned to hospital for planned surgery several weeks or months later, with a few readmitted in emergencies.

The type of care provided by the parents varied according to the child's clinical condition. Each child's condition(s) and the medical procedures their parents performed are listed in

Table 5.1 with further information given in Appendix 4. Appendix 5 explains in more detail what the medical procedures the parents performed involved.

Table 5.1 Participant demographics and information about the children's needs

Participant identifier	Condition & surgeries	Medical procedures carried out	Child's age at interview	Parent's age at interview	No. of children
01 (Mother)	Exomphalos & auditory neuropathy disorder	Tracheostomy & nasogastric feeding tube	18 months	34	2
19 (Mother)	Exomphalos & a rare heart disease	Nasogastric feeding tube & Percutaneous endoscopic gastrostomy (PEG)	16 months	36	3
04 & 05 (Mother & Father)	Exomphalos & tracheomalacia (floppy windpipe)	Oxygen & Jejunostomy	7 years	36 & 34	2
18 (Mother)	Hirschsprung's disease	Bowel washouts	1 year	36	2
28 & 29 (Mother & Father)	Hirschsprung's disease	Bowel washouts	18 weeks	35 & 34	2
22 (Mother)	Hirschsprung's disease	Bowel washouts & anal dilations	16 months	31	2
20 & 21 (Mother & Father)	Hirschsprung's disease	Bowel washouts & anal dilations	19 months	40 & 39	3
39 & 40 (Mother & Father)	Hirschsprung's disease	Bowel washouts and stoma care	5 years	33 & 48	1

24 (Mother)	Congenital diaphragmatic hernia	Tracheostomy, ventilation and gastrostomy	9 years	39	4
14 (Mother)	Diagnosis unknown	Stoma care	6 months	42	1
35 (Mother)	Blood loss to bowel, necrotising bowel	Total Parenteral Nutrition (TPN)	7 years	41	3

5.2.2 Analysis

I undertook a thematic analysis of the transcripts, using the steps laid out in Ziebland and McPherson's paper on analysing personal experiences of health and illness (Ziebland & McPherson, 2006). This approach is suitable for analysing secondary data and ensures every instance, include negative evidence ('deviant cases') are included in the analysis. The analyses was overseen by my supervisor Professor Charles Vincent (CV), Dr Lisa Hinton (LH) a senior qualitative researcher in the Department of Primary Care, and Dr Emily Harrop (EH), a Consultant Paediatrician who works with families with complex medical needs. I first read through the interview transcripts noting down potential themes and then coded the interviews with the support of NVIVO v12 (software for qualitative analysis), developing a coding framework iteratively in discussion with CV and LH. The research question was focused on the experiences of parents caring for children at home: parts of the transcript which were irrelevant to the research question (e.g. descriptions of the birth) were not coded. The data was organised under anticipated and emergent themes, using constant comparison techniques to group the data. The codes were revised through an iterative process. For each theme, a 'one sheet of paper' (OSOP) analysis was conducted (Ziebland & McPherson, 2006). Summaries of each code were

then written and re-written and discussed with the research team. Each code was illustrated with quotes.

5.3 Results

Parents described facing a number of challenges when caring for children with complex medical needs. The first theme explores parents' responsibilities, the second looks at the impact on daily life and the third explores the parent journey over time. Table 5.2 shows illustrative quotes for each theme to give an overall sense of the coding structure and challenges faced by families.

Table 5.2 The themes and subthemes with illustrative quotes

The responsibilities of the parent	Performing medical procedures	*You try pinning a 14 month old and jamming a [nasogastric] tube down her nose, it's not nice for anybody especially when they can scream at you and the more she screams the less it will go down.* (ID19)
	Managing emergencies and problems	*His body was all limp and we couldn't wake him and he was completely unresponsive and we knew that he was like being poisoned and at that point we were like we have to do a flush out immediately we don't even have time to get him to hospital*. (ID39&40)
	Co-ordinating care	*The go between for everyone is the parent and as the parent that's an awful lot of responsibility and an awful lot of information you have to remember. (*ID19*)*
	Advocating for your child and fighting the system	*We still have someone in overnight we get five nights a week [um] which we have to fight for on a regular basis which is the odd thing because we had a fight to get him out of hospital and then six months down the track they were trying to reduce his, his package having told me, you know, for three*

		years I can't take him home because he needs someone overnight. (ID24)
Impact on daily life	Constraints on time	*My GP has said 'Would you like some counselling?' and in the same breath he said 'Can you fit it in? it's just going to be another appointment to you?' You're right I haven't got time to talk to anyone about how I feel because I'm too busy looking after my kids and their hospital appointments, I just don't have time.* (ID19)
	The challenges of going out	*And I thought 'How can we go anywhere, we've got suction pumps, we've got oxygen tanks, we've got, more medical stuff for feeding things than you can shake a stick at.' If we went anywhere we had to have three pushchairs and four adults for one baby to carry everything, so we just didn't go out.* (ID19).
	Lack of sleep	*And over time, just the exhaustion of trying to [um] look after him just got increasingly tough and unmanageable and, actually, to the point of being quite dangerous because, obviously, you have to be awake and alert and ready to change his [tracheostomy] tube or give him suction at any time. (*ID01*)*
	Impact on other siblings	*I go upstairs to say goodnight to him [other sibling] …he's already fast asleep and I think yeah, and then I go downstairs and spend another half an hour with [daughter] doing all her procedures and think yeah he missed, he missed us yeah.* (ID35)
The parent journey over time	Becoming an expert	*So by doing it for a week at home even, where it's just you, you are actually becoming more experienced and better at doing it than the staff just by the number of times you do it. And then when you get to a stage where you've been doing that for two months, you know, you are the best person who could possibly do it*. (ID28&29)
	The new normal	*It's been really tough on family life but equally we've had days were we've sat in the back garden and everyone's been out and we've gone 'Ooh look*

		for five minutes we're just a normal family' and then [Name] will throw up and [Name] will dislocate her shoulder [laughs] [Name] will scream because she's too tired. (ID19)

5.3.1 The responsibilities of the parent

Parents had numerous responsibilities beyond those most parents have for their child. These included performing medical procedures, managing emergencies, co-ordinating care and advocating for their child. These responsibilities would traditionally be held by healthcare providers, who in comparison to parents, receive far more training and ongoing supervision. The sense of responsibility parents felt was particularly acute in the period following discharge from hospital, when parental confidence was still building and routines were unfamiliar. For some parents, there was a real sense of being alone in these responsibilities.

5.3.1.1 Performing medical procedures

Table 5.3 details some of the descriptions parents gave about the medical procedures they perform for their child. Many tasks were technically and emotionally demanding for parents especially in the early days of caring for their child. This was particularly true for procedures which were perceived to be painful or distressing for their child. Some parents rationalised this by thinking about the long-term gains.

I don't think I could do the dilations that was [Partner]'s job to do… he [child] used to scream when we first started doing them, it was a horrendous scream and I would sort of have to go out of the room I couldn't, I couldn't bear it and, but you do just have to switch off and you're doing it so it that in the future he's, he's well. (ID20&21)

The procedures parents had to carry out had been done by nurses and doctors in hospital. One parent commented that "*you are basically just being a nurse*" (ID04&05). Some had been trained how to perform medical procedures in hospital as part of their preparation for going home, whereas others had limited experience. Most were daunted by the sense of responsibility when they first did the tasks at home, without the back up of healthcare professionals.

Suddenly we had to do it all… when neither of us have barely any medical training whatsoever… I was confident doing it in the hospital but it's different being confident doing it an environment where you have lots of medical professionals to help you if you get stuck, to doing it by yourself at home, alone.(ID19)

Some felt they had not received enough training and some of the problems they experienced could have been avoided with more preparation before going home.

We didn't know what we were doing… we felt a bit out of our depths… it was a lot of trial and error with the [stoma] bags as well [um] a lot of leaks… a lot of getting up in the night and having to get him in the shower and wash him down and looking back on it that was unnecessary… if we had had the support, the correct training and support.(ID39&40)

Table 5.3 Parents descriptions of the medical procedures and tasks they do for their children

Passing a nasogastric tube	*And the first time I pulled the NG tube out was in the middle of the night in the dark two days after we brought her home… it was awful my husband pinned her head down I jammed the tube in hoping that I hadn't hit her lungs and that I'd hit her stomach.* (ID19)

Dilations	*We had to use a dilator with her every day which is like a metal thing that you poke up her bottom to make sure it doesn't shrink but it did shrink. So then we had to and again the worst possible outcome there is more surgery to stretch the bowels. So [um] yeah we had to use a bigger dilator and do it more often and those things were really, really awful.* (ID18)
Bowel washouts	*Oh a special kind of horror really… we would do his wash out and the wash out can take anywhere from about 20 minutes to an hour… You do a wash out at 10:00 and one at 6:00… And sometimes even three times a day if he particularly distended, you know... it's definitely a two man job…I think doing it that way was way preferable to him being in hospital I absolutely, I mean it was a pain… it's not an easy thing, it had to be said.* (ID28&29)
Stoma care	*You're afraid of kind of tearing the wound or hurting something and then the stoma would bleed and you kind of have to get used to the fact that it's bleeding.* (ID14)
Total parenteral nutrition	*We've also had times where, you know the giving set has broken so, you know she's, the TPN is just leaking into the bed and she, you know, her central line is just essentially open to the air, you know, she could bleed out, she could get air in her line.* (ID35).
Medication management	*She was having several different tablets or... it wasn't tablets, it was all liquids but medications a day and at lots of different intervals… and that was always quite stressful organising that.* (ID04&05)

5.3.1.2 Managing emergencies

One of the most psychological challenging responsibilities parents faced was managing emergencies. Some parents had to manage life and death situations at home, including one parent who was responsible for administering home oxygen when her child deteriorated.

She [child] would go mottled and she'd go blue and she'd whimper and then … her oxygen levels would drop [um] and then her peripheral pulses would go [um] and she'd just lie and whimper [um] hence we had the home oxygen. (ID19)

All parents were responsible for making decisions on when to seek help from medical professionals. Some were worried they might not detect problems and call for help quickly enough, including one parent who described lasting trauma from an incident which led to her child being resuscitated.

By the time we got to the hospital [name of child] was so shut down they could only find a vein in her head [um] and she had to be resuscitated… she was so close to dying and I hadn't realised how close to dying she was … that was the single worst time of everything the whole lot and that's the memory you have when you're lying in bed thinking about your mind works overtime, that memory there, that makes me stop in my tracks. (ID19)

Decisions on when to seek help are complicated by the fact that General Practitioners (GPs), Accident & Emergency (A&E) and out-of-hours/after-hours care often lack the specialist knowledge required to advise parents on how to treat these children. Some parents felt they should have received better preparation for dealing with problems and emergencies themselves.

5.3.1.3 Co-ordinating care

Parents are responsible for co-ordinating all aspects of their child's care. Some families had a complex web of healthcare professionals involved, with one parent (ID19) noting that there were '*21 consultants'* involved in her child's care. Parents become the only one who understood the complex "map" and become the communication link between the professionals.

So a while back I drew like a mind map of all the professionals who are involved in [son]'s care and everything and [um] if, if needs be, I can show that to people. Actually, it's quite a powerful way of demonstrating the complexity of, of what you have to deal with. (ID01)

Families had numerous appointments and visits to manage, with some having 2-4 appointments each week. Arranging, prioritising and attending all these appointments was time consuming and brought with them a multitude of logistical challenges.

Parents were also responsible for complex medication regimes. Some parents experienced difficulties getting prescriptions for rare and specialist drugs and felt they had to advise GPs and make decisions about medication changes themselves.

I had to frogmarch her in to the surgery one day and tell the doctor I wanted ranitidine because she had silent reflux, you know, my, my responsibility, my decision, just give me the medicine. And this poor young doctor looked petrified but he gave me the prescription and it worked and thank god because it was, I guess it was a bit of a guess on my part as well. (ID18)

As well as medication management, parents were also responsible for managing supplies and regular deliveries, and there were often hiccups. Homes became medical spaces, storing these vital supplies.

We were having loads of trouble with the supplier, they were throwing our supplies over the back gate when it was raining… So the boxes were getting wet and I was calling them and I was like 'I can't use stoma bags that have been outside in the rain you're gonna have to re-send them' (ID39&40)

5.3.1.4 Advocating for your child and fighting the system

Parents advocated strongly for what they felt was best for their child and family. Parents wanted to feel they were able to make decisions and sometimes got frustrated when they felt the rules and regulations were being applied without flexibility. In some cases

there were disagreements between parents and healthcare professionals. For example in one instance, healthcare professionals threatened to report the parents to social services citing safeguarding concerns because the parents wanted to care for their child at home rather than in hospital.

We said well this is ridiculous we're not doing this and they said well at that, at this point then that becomes a child protection issue we're gonna have to bring in Social Services because you're refusing medical care for your child. (ID28&29)

Parents were their child's advocates in other aspects of life, such as education. Some felt like they were constantly fighting. If they disagreed with a decision made by a healthcare professional or another authority, they were threatened. The constant fighting had serious psychological impact on some parents.

We received a letter in the post saying we're reducing your [care] package to three nights… If you don't agree with what they're doing, if you say no to anything then they just, they, you know, threaten to take your package away and bully you until you do what they want. So we've actually have the MP involved now to see whether, you know, she can sort it out because at the time when they did that with the bed I ended up having panic attacks and I [um] I was really, really, really distressed, you know. (ID24)

5.3.2 The impact on daily life

The impact on day-to-day life for families was substantial. There was not enough time to do everything that needed doing, going out the house became difficult and for some, sleep-deprivation became a common feature of life. The care needs of the child placed constraints on many aspects of life, and impacts were felt on the whole family. Parents were particularly concerned about the impact on other siblings.

5.3.2.1 Constraints on time

Lack of time was a dominant feature of parents' narratives. There was simply too much to do: arranging and attending appointments, managing equipment deliveries, looking after other siblings, washing clothes and bedsheets for children with incontinence and finding time to do household chores.

I seemed to be very busy like [um] she did go through tons and tons of clothes obviously because they all got leaked with bowel fluid all the time… so I was washing her clothes, drying her clothes, sorting stuff out, you know, waiting for the next doctor, waiting for the next nurse, waiting for hand over, changing her nappies, getting the nappies weighed,… I don't know where the time goes but you are like incredibly busy. (ID35)

Over time parents developed routines. Some felt others (e.g. healthcare professionals, friends and those who commission or manage healthcare services) did not realise just how much they had to juggle and how little time they had. Parents often had no time for themselves.

"There has been days where I, where I've gone 'Enough. If I don't leave this house for five minutes and go and get some fresh air I'll actually not come back' because there's so much in your head and the times where you do have five minutes to sit down and relax you're on the exomphalos [condition affecting the abdominal wall, see Appendix A] support group checking up on other people's kids… so the time when you do have as your down time, my respite care, I spend most of my respite care running to and from school dealing with my other children." (ID19)

5.3.2.2 The challenges of going out

Families were unable to leave the house and go out with their child after coming home from hospital. There were practical constraints such as being unable to carry all the medical equipment or not being able to take their child out due to infection risk, and psychological reasons for not going out, especially soon after coming home from hospital.

I was afraid to take him out for long periods of time because I didn't want to have to do a nappy change or a stoma bag change in a public place. Not just because it is so messy but also I didn't want other people to kind of be able to see me doing a stoma bag change. (ID14)

Over time going out became easier, although life had to be fitted around time-specific medical procedures, and practical challenges, such as worries about the risk of infection, remained. Participant 35 described the detailed planning required to make activities possible, such as going swimming or on a family holiday. For some, it was important to stay near to their specialist hospital in case there was a problem.

Some felt they could not go anywhere without their child, as it was too much responsibility to leave them with a relative or a friend. Others felt confident occasionally leaving their child with a trusted family member, but they did not go far in case there was a problem.

We don't leave her [daughter] at all when she's connected so we can't go out in the evenings when she's on an infusion just because it's too difficult and it's too much responsibility really for other people [um] and like we say we've had all of these different things go wrong over the years and although they're rare… they're quite life threatening (ID35).

5.3.2.3 Lack of sleep

Lack of sleep was a real struggle for some parents, especially soon after coming home. Some children had ongoing medical needs that needed attending to at night, such as giving feeds and medications, or responding to equipment alarms. There was a lot to do even at night-time. Parents were constantly alert. One parent described sleeping with the light on sitting up (ID04&05).

The children with tracheostomies had care packages which provided paid carers for a set number of hours a week. Not all parents were able to trust the carers enough to sleep: after an error made by a carer, one parent fitted a video camera to monitor overnight care.

I said I'm sorry I cannot go to bed and leave [son] down here with him [the paid carer] all the time cos when, on the nights that he was here as well we'd have a video camera in there and I didn't sleep because I was so worried. (ID24)

Lack of sleep had a wider impact on parents, such as on their relationship with their partner and their children. One parent (ID24) was prescribed antidepressants to help her sleep. A few remarked on the dangers of performing medical tasks when they were so tired.

On one tube change occasion, I put in a smaller [tracheostomy] tube rather than the right tube size and didn't notice for a couple of hours [um] and I thought then, this is actually dangerous. I can't do this anymore. (ID01).

5.3.2.4 Impact on siblings

Concern for the impact on other siblings was a key feature of parents' narratives. They felt guilty and torn: they had to prioritise the needs of their medically complex child, and didn't have enough time to spend with their other children.

They [younger siblings] were screaming because they wanted feeding but I had to deal with [son] because otherwise he, you know he'd be coughing and he'd vomit and then he wouldn't he'd drop his oxygen and then he, you know, wouldn't be able to breathe so again it's all, when it's always been where you've had to pick [son] over the other kids. (ID24)

Most parents reflected that things had been hard for the siblings, for example feeling other siblings had grown up quickly, or played up for attention. Parents were concerned about siblings watching distressing procedures, and long-term trauma, as well as the impact their own mental health and lack of sleep was having on their children.

I know my teenage daughter definitely suffers from it [PTSD] cos she can't stand to look at [Name]'s tubes, she can't stand to be in the room when the children are crying. (ID19)

Parents did what they could to help their other children to cope, for example some tried explaining the medical procedures to their children to help them understand what was happening. Others described strategies for keeping their other children busy so they could concentrate when they did procedures.

She [sibling] has seen the, the dilator and I've explained it's to make [Baby 2]'s bum well and [um] cos she's at that stage of 'What's that' and 'What's happening' and 'Why's that,

what's that, why's [Baby 2] crying' and things and so, you know, we've just, just explained it as well, best we can. (ID20&21)

5.3.3 The parents' journey over time

Parents invested a lot of time and effort in developing substantial expertise in the medical needs of their children, and felt that aspects of their expertise exceeded that of clinicians. Parents were on a journey to find a new normal for their family as they tried to make sense of their new reality which few others understood.

5.3.3.1 Developing expertise

Parents became experts in their child's medical needs by doing procedures daily, learning through trial and error, and doing extensive research. They used a range of sources, including online information, advice and recommendations from their peers, and journal articles. Over time, many developed more expertise than the professionals. They wanted their expertise to be valued by professionals.

Don't undervalue the amount of time and energy [um] that parents put into trying to find out as much as they can and also knowing their child inside out and back to front. (ID01)

Parents developed expertise in managing and responding to problems, and detecting early warning signs and became increasingly confident in medical decision making.

As parents developed expertise, some also became very wary of the care given to their child in hospital or by other professionals and carers. For example, one family (ID28&29) describe the distress caused to their child during a bowel washout performed in hospital.

It was absolutely brutal…clearly someone who is mostly used to doing things on unconscious people, you know, and he [child] was hysterical in the end. (ID28&29).

5.3.3.2 The new normal

Parents were on a journey to find a new normal as they adapted their lives. The pursuit of normality was a key feature of their narratives. Some families talked about normal life returning, in relation to their child's condition getting better or being able to go out and do everyday things. Feeling like their child was 'normal' was important to some: they made references to 'normal' activities their children (or other children with the same condition) do, like playing football. Others reflected that their normal wasn't necessarily what others saw as normal, but something they had come to accept.

He'll be fine, it will be fine, they're just a different normal. (ID20&21)

Parents reflected on the differences between their family and others. For example, not being able to go out occasionally and leave their child with someone else, like "*normal married couples*" (ID39&40). Family roles changed as families adapted to a new normal.

Yeah he does "team well" [husband] and I do "team ill" that's very much the balance now, he gets all the kids who are well that day and goes out and does stuff and I keep the kids who are ill and need medical attention. (ID19)

For some parents, chronic stress was an enduring part of their new normal.

It's like because you're living on the edge all the time, the littlest curve ball that is thrown into the mix just sends you over the edge. (ID24)

Some parents felt that they weren't told about the realities of caring for a child with complex medical needs, or that the picture that was portrayed to them doesn't match reality. Many felt that healthcare professionals, commissioners and friends don't understand their reality.

We knew that we would have a lot of obstacles to face…I did not anticipate our life to become completely and utterly consumed by medical needs. (ID19)

5.4 Discussion

5.4.1 Summary

The analysis reported in this chapter provides valuable insights into parents' experiences of the challenges of caring for children who need complex medical procedures at home. Parents take on substantial responsibilities well beyond those most parents have for their children. They have to learn to do technical and distressing medical procedures, manage emergencies and co-ordinate their child's care. They become advocates so they can navigate and fight the complex health and care system. Their responsibilities have an enormous impact on the family. There is often too much to do and not enough time. Some parents become chronically sleep deprived and engaging in normal activities is very difficult. However over time parents can become experts in their children's medical needs and adapt their lives to a new normal. The interviews provide insights into the early experiences of parents performing medical procedures for their child, and the later development of expertise.

5.4.2 Burden of treatment

Burden of treatment theory was originally developed to describe the work of patients with chronic conditions (and their caregivers) who are increasingly delegated tasks previously undertaken by the healthcare system, such as self-monitoring, drug management and passing information between healthcare professionals (Mair & May, 2014; May et al., 2014, 2009). The parenting of children with complex medical needs is similarly complex and burdensome, and has been described in one study as 'intense parenting' (Woodgate et al., 2015). The capacity of families to take on these

responsibilities is dependent on many factors such as the medical complexity of the child and the psychosocial complexity of the family (Altman, Zurynski, et al., 2018). An additional challenge for parents of children with the most complex needs is that hardly anyone else has the expertise to care for their children. This contributes to a substantial sense of responsibility and means that parents are isolated and cut off from normal support networks. Parents are taking on significant responsibilities, many of which are within the remit of highly-trained professionals in hospital settings, but given comparatively little support and preparation.

Parents learn to navigate the complex health and care system and become advocates for their children. As other studies have found, the burden of navigating the system can have a negative impact on parents' mental health (Altman, Zurynski, et al., 2018). May and colleagues described burden of treatment as the ability to exploit opportunities to utilise healthcare service. Parents in this study similarly had to develop structural resilience (potential to absorb adversity), social capital (informational and material resources), social skills (securing co-operation) and functional performance (potential to do the work) (May et al., 2014). The healthcare system may sometimes appear to try to control parents (e.g. by involving social services or threatening to take away a care package as was the case in the interviews) which can lead parents to feel they are "fighting the system". Studies from other countries have also found that parents feel they are fighting the system (Currie & Szabo, 2019; Dybwik et al., 2011). Systems, and the rules and regulations which govern them, are often created around services, rather than designed to meet the needs of children and families. Co-ordinating care and advocating for their child becomes a time-consuming endeavour for parents and adds to the burden of care.

5.4.3 Support for parents

Families have substantial expertise that needs to be valued and listened to (Hinton & Armstrong, 2020), but they need help to ease the burden of care. Several families in the interviews felt that some of the difficulties they encountered could have been avoided had they received better or more preparation and support for the responsibilities they take on. Parents need to feel confident in their abilities, as well as have the competence to perform the necessary tasks. Access to high-quality information and specialist medical professionals is critical. There is a clear psychological impact on the whole family which needs to be core to the preparation and support parents receive. The interviews indicate that parents also need support with their other responsibilities, e.g. co-ordinating care and navigating the system. The parents in the interview did not always feel safe leaving their child with others (e.g. paid carers, family members, respite services), suggesting that high-quality training for staff also needs to be more readily available.

5.4.4 Strengths and limitations

The open narrative approach to the interviews enabled me to uncover rich insights into the experiences of parents caring for children who require complex medical care at home, despite the fact that the interviews were originally conducted to answer a different research question. Some of the findings clearly resonate with themes identified in other qualitative studies, e.g. feeling you are fighting the system and parents' experiences of doing distressing procedures (Dybwik et al., 2011; Spiers & Beresford, 2017; Woodgate et al., 2015). Parents of children with complex needs have limited time and can be difficult to recruit; by conducting secondary analysis of existing interviews I have maximised the utility of participants' data (Ziebland & Hunt, 2014). The sample covered a wide range of ongoing needs and medical procedures so the findings may

transfer to children with other conditions, beyond abdominal surgery which was common to all the children in our sample (Polit & Beck, 2010). The range of ages of the children at the time of interview meant that we captured parents' experiences at different time points, but conversely meant that not all participants could reflect on the long-term impacts.

5.4.5 Reflexivity

Reflexivity in qualitative research refers to critical self-evaluation on how the researchers' position (e.g. their personal experiences) affects the research process and outcome (Berger, 2015). In qualitative research knowledge production is not independent of the researchers producing it (Berger, 2015). The analysis presented in this chapter was conducted primarily by myself, a psychologist who is conducting research on support for parents of children with medical complexity. My extensive knowledge of the subject area meant I was well-placed to identify anticipated themes to enrich the analysis, as well as emergent themes from the data. The analysis was overseen by a second researcher LH, an experienced social scientist and qualitative researcher who conducted the original interviews. This meant that the analysis could be checked against the insights from the original interviewer from 'being there'. The analysis was also overseen by paediatrician EH so that the findings could be checked against the experiences of a clinician who works with children with medical complexity who confirmed the analysis 'rung true' with the experiences of families she works with.

5.5 Conclusions

This analysis of parent interviews provides a rich description of the challenges families face caring for medically complex children. The responsibilities placed on parents are

clearly substantial. Parents' descriptions of managing procedures and emergencies demonstrates the emotional toll on families and the need for more preparation and support. There are serious psychological impacts on the whole family which need to be integral to any training and support for families. Parents need to be better prepared and supported to take on these new responsibilities. The next chapter will examine parents' training and support needs in more detail through online surveys with families.

Chapter 6 Parents' experiences of training and support, and their recommendations for improvement: two online surveys with families

6.1 Introduction

This chapter presents data from two online surveys with parents who provide specialist medical care for their children exploring their experiences of training and support. The previous chapter presented an analysis of interviews with parents on the challenges they experience caring for a child with complex medical needs. Before we can develop interventions for improving training and support for families, we need to understand more about the training and the ongoing support parents currently receive for the specialist medical care they provide for their children. The literature suggests that training for parents can be variable, with some authors arguing for more comprehensive training (Evans et al., 2012; Glasson et al., 2020; McDonald et al., 2016). However there is limited data published in the literature describing families' experiences of training and support in detail. We need a better understanding of the training parents in the UK currently receive, and their views on how this could be improved.

6.1.1 What do we know from the literature about training for parents who do specialist medical procedures for their children?

There are a small number of descriptive studies in the international literature which give some indication of how parents are trained to provide specialist medical care for children. Studies suggest training is quite variable, and that families are largely reliant on training from nurses typically in hospital and then receive limited follow-up, with families learning through experience, further independent research and peer support (Boland et al., 2017; McDonald et al., 2015, 2016). The literature also suggests that some families experience

difficulty learning to perform procedures which are distressing or painful to their child (McDonald et al., 2016; Spiers & Beresford, 2017). One study specific to home enteral tube feeding (with adult patients and carers of children in Ireland) reported that training was delivered by a mixture of hospital nurses, dieticians and nutrition company representatives (Boland et al., 2017). The survey found that the majority of patients were given written information before discharge from hospital and that families reported using online resources for further support including YouTube videos, closed Facebook groups and parent support groups within the paediatric cohort (Boland et al., 2017).

The existing literature gives some indication of families' experiences of training but cannot provide an in-depth description of the UK context for families learning to care for a child who requires specialist medical procedures at home. The surveys presented in this chapter seek to characterise in detail the training and support parents currently receive in the UK which is a critically next step for informing the development of a training and support package which is the ultimate aim of my thesis. These surveys will give some indication of what types of training families receive and rate as helpful, and crucially also identify parents' recommendations for how training and support could be improved for parents new to gastrostomy care.

6.1.2 Study aims

In order to better understand the range of parents' experiences of training and support, this chapter reports on data from two online surveys with families across the UK. The aim of the first survey is to explore parents' experiences of learning to care for their child across a range of different medical procedures (e.g. feeding tubes, tracheostomies, ventilation) and to explore the emotional impact on families. This first survey provides a

foundation for the second larger survey which focuses specifically on gastrostomy care. Gastrostomy care is the focus of the training interventions developed in subsequent chapters. The second survey reports on a larger sample of parents who care for children with gastrostomies (n=146). The second survey has two distinct aims. The first aim is to understand the variability in parents' experiences of training and ongoing support for caring for their child's gastrostomy across a large sample of UK families and the second aim is to understand parents' recommendations for improving training and support.

6.2 Survey 1: Parents' experiences of learning to provide complex medical care

6.2.1 Methods

6.2.1.1 Survey Aims

The aim of this first survey was to explore parents' experiences of learning to care for their child across a range of different medical procedures (e.g. feeding tubes, tracheostomies, ventilation, home oxygen) and to explore the emotional impact on families.

6.2.1.2 Survey development

The online survey was developed in stages. In the initial exploratory stage I conducted two exploratory interviews with parents who care for a medically complex child, reviewed the literature and set up regular meetings with parent representatives and nurses and paediatricians from the community and hospital who support children with complex medical needs to inform the direction of the research. The survey was drafted, piloted and revised in consultation with a parent representative, the charity Well Child and a paediatrician from the community, who were asked to comment on the suitability

of the questions, readability and length. Recruitment strategies were developed based on advice from our parent representatives, clinicians and relevant charities (e.g. Well Child).

6.2.1.3 Survey design

The survey consisted of predominately qualitative, open-ended questions and a few quantitative close-ended questions. The survey was intended to be exploratory and inform the development of the second survey. The survey asked participants questions on: i) the types of care they provide for their child, ii) which tasks they find most difficult, iii) their experiences of learning to provide this care and any training you received, iv) emotional aspects of providing care and v) ongoing experiences and support.

6.2.1.4 Participants

Families were recruited via national UK charities and local charities who posted on Facebook groups and Twitter, circulated the survey through newsletters and emails, and posted on their websites. The full list of charities is provided in Appendix 6. Some parents also choose to share the survey with friends and family members.

In order to take part in the first survey participants needed to be a family carer (e.g. mother, father, grandparent) who provided specialist healthcare in the home to a child under 25 years. A list of common tasks was developed in consultation with clinicians (see Appendix 7). Participants needed to do at least one of the tasks on the list in order to participate. Family carers needed to be at least 18 years of age. Participants were not paid for their time.

6.2.1.5 Ethics

All participants gave informed consent before taking part and consented for their data to be used in publications. Ethical approval for the study was received by The Medical

Sciences Inter-Divisional Research Ethics Committee at the University of Oxford (Reference: R56623/RE004).

6.2.1.6 Analysis

Descriptive statistics were computed for all close-ended questions, using SPSS Statistics 25. Participants who did not complete the full survey were excluded. The open ended questions were coded in NVivo 12 using inductive content analysis, to group responses based on surface level of meaning (Elo & Kyngäs, 2008). Answers were coded by units of meaning, and grouped into categories emerging from the data. These were summarised in the text and illustrated with quotes from participants.

6.2.2 Results

6.2.2.1 Participants

Forty-one parents completed the first survey. The age of their children ranged from 0 to 25 years: 10 (24%) were 0-4 years, 17 (41%) were 5-10, 10 (24%) were 11-16 and 3 (7%) were 17-25. The families came from a range of different regions in the UK. Most of the responders were mothers (*n* = 38, 93%), 2 were fathers and 1 was an aunt. The number of different healthcare tasks parents said they did ranged from 1 to 17, with a median of 5 tasks. Table 6.1 shows a list of healthcare tasks from the most common to the least common. Feeding tubes, home oxygen and suctioning were the most common procedures. More background information about the families is given in Appendix 8.

Table 6.1 List of specialist medical procedures family carers indicated they perform for their child

Tasks parents do in the home	**N**
Gastrostomy (e.g. PEG/button): giving feeds and/or medications, care of the skin around the gastrostomy etc.	35
Gastrostomy: inserting new buttons	26

Oral suctioning	19
Oxygen or high flow nasal cannula therapy	19
Nasogastric feeding tubes (NG): giving feeds and/or medications	18
Nasal suctioning	15
Nasogastric feeding tubes (NG): inserting/passing new NG tubes	12
Deep suctioning	12
Non-invasive ventilation (e.g. via face mask or nasal cannulae/nasal pillows)	11
Enemas or bowel washouts	10
Routine changing of a tracheostomy tube	7
Ventilation via a tracheostomy: ventilation, care of skin around site, tracheostomy suctioning, changes of tracheotomy tie, etc.	6
Intermittent catheter management	6
Changing ventilation settings (e.g. pressure or rate)	5
Intravenous injections	5
Subcutaneous injection	4
Indwelling catheter management	3
Bladder washouts	2

6.2.2.2 How parents felt in the first week at home providing care for their child

Participants were asked how they felt in the first few weeks of providing care at home. The overwhelming majority of parents were scared, ranging from "*a little worried" to "terrified, out of my depth."* Some parents described feeling isolated and exhausted. A few commented on the fear of getting something wrong: "*Terrified we would do it wrong, we weren't really sure what was right or wrong*." One parent described the acute sense of responsibility they felt especially when they had to manage emergencies: *"Utterly terrifying! The responsibility was crippling. The thought that her life was solely in our hands was horrific and I felt totally unqualified and highly emotional".* A few of the family carers described more positive emotions, including feeling confident and prepared, and focusing on the positives: *"Scared but confident and proud that as her Mum I was still able to do the most natural thing in the world and take care of her*."

6.2.2.3 Types of care parents found difficult

Participants were asked to reflect on which of the medical procedures they do they find most difficult and why. Tasks which children find distressing or painful were commonly mentioned as being difficult, such as passing an NG tube or changing a gastrostomy button: "*I find it really difficult to carry out these tasks when I'm the parent and having to inflict these procedures on my child which may cause pain/upset."* Another common answer was the difficulty of managing emergencies and safety-critical tasks: parents were worried about the risks involved. For example one parent said they found intravenous (IV) antibiotics difficult because of "*the scary potentially catastrophic consequences if mistakes made*." Some parents mentioned the technical difficulty of tasks, ("*needed a "knack" which took a while to learn*"), as well as the difficulty of doing procedures when children are uncooperative or are moving around a lot. A few parents talked about the time-consuming nature of tasks and a few said nothing was difficult anymore.

6.2.2.4 Worries about making mistakes

Participants were asked to what extent they worried about making mistakes. Just three (7%) family carers said they never worry about making mistakes when providing care to their child. Almost half 20 (49%) said they worry a little, with 8 (20%) saying they worry a bit and 10 (24%) saying they worry a lot. The family carers worried more about others making mistakes than making mistakes themselves. Over half (22, 54%) of family carers worried a lot about others making a mistake when caring for their child. Some of these concerns related to paid carers, some to hospital staff, schools and GPs. Parents described past experiences where others had harmed their child and not been able to perform the necessary care: "*We've had 2 people freeze in situations one where his trachy was blocked and she 'couldn't' sort it out and one where his trachy came out and she*

didn't know what to do - these were both highly trained and when it came to it, they couldn't 'do' their job. Both times, I jumped in to save his life. I worry that this would happen outside whilst at school when I'm not there to help. Its a horrific feeling for me." It is clear than some parents really worry about the expertise of others involved in their child's care.

6.2.2.5 Parents' experiences of training

Parents were asked to describe their experiences of training and support. Box 6.1 shows some examples of good and poor training from parents' descriptions in the first survey. Commonly mentioned methods of training were demonstrations and supervised practice. Some families received training in hospital, some in the community and a few in both locations. Training was given by a variety of different people include CCNs, hospital nurses, feeding companies, and dieticians. Some family carers mentioned a process of being "signed-off" as competent by a healthcare professional. Some participants said their training did not prepare them well for problems or emergencies: "*It was difficult because generally you can only really learn what it's like when you're in that medical emergency. We were taught how to suction when [our child] was stable. The nurses weren't there when she was seizuring and the sole responsibility was ours! It's totally different suctioning when she's in good health and stable."* One parent reflected on the limitations of training in the hospital for preparing you to care for a child in the home environment: "*Real life situations are very different than in a classroom or hospital setting - you may not have a clean surface to lay things out on or they may be sitting up and not able to lie them down for instance*."

Box 6.1: Descriptions of training

Examples of good training:

"We had good support from our local hospital and main surgical hospital making sure we were confident in these tasks, before being discharged, helped by the fact we were in hospital so long we had plenty of time to practice!"

"We had step by step training at [hospital name] on the ward in the (long) preparation that it took to get us home. This was done day to day and practically so we were involved in all of his cares under the watchful eye of the nurse on duty and as and when we were confident, we were signed off."

"Resus training with dolls including those with tracheostomies. Handout leaflet describing steps to take with trache change. Practical demonstrations including a simulated change."

Examples of poor training:

"We were given one lot of guided practice in hospital prior to discharge for using the button. I observed our Community Children's Nurse (CCN) change a button once and then I have continue to manage this."

"We were shown on the ward and sent home to get on with it."

"Minimal training given while on a hospital ward. Told how to do these tasks then left to it."

"NIV putting mask on & using machine I was self-taught, no training was offered until I was already fairly confident."

"I learned by reading a book on how to."

6.2.2.6 Parents' experiences of ongoing support

Family carers were asked about the support they received from healthcare professionals. There was a marked difference in how well-supported families felt during working hours vs. out of hours, with much less support available out of hours (see Figure 6.1). Families were asked who they would contact in an emergency. Answers were highly variable, ranging from 999 and A&E to specific hospital wards, nurses and paediatricians who knew the children. For non-urgent problems, most families said they would contact the CCN

team. Some also mentioned school nurses, specialist nurses, GPs, Consultants and Paediatricians. Families mentioned various charities and Facebook groups as other sources of ongoing support.

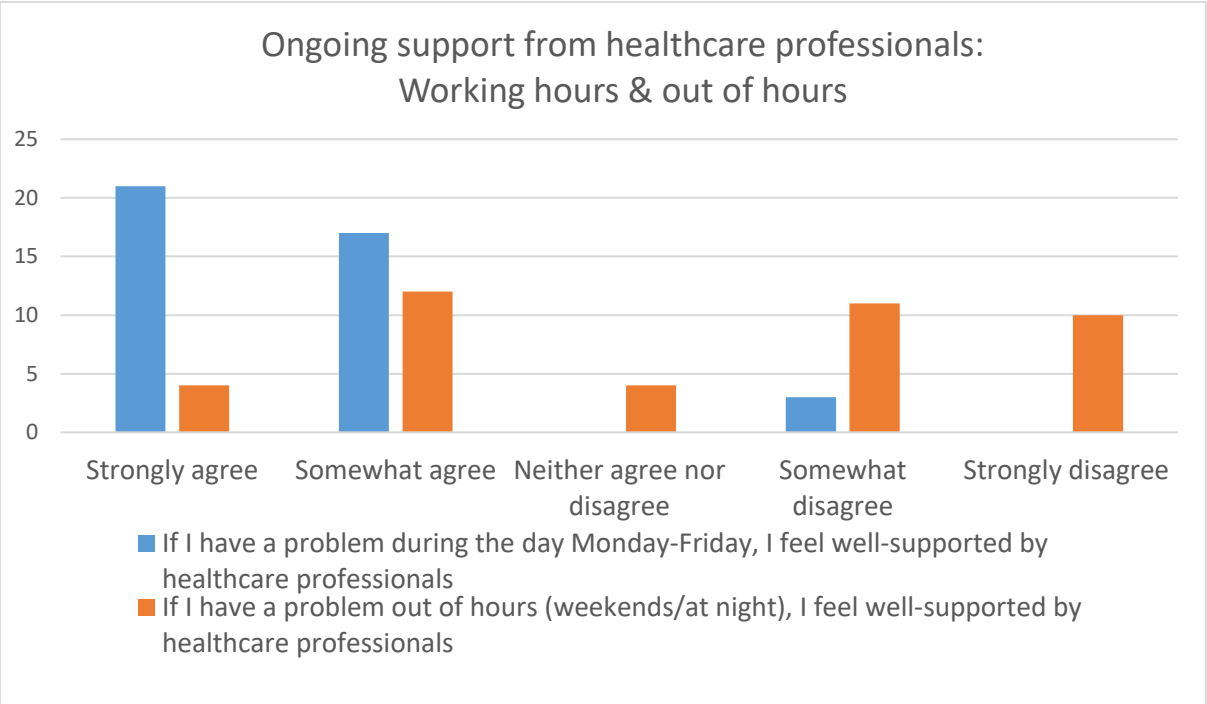


Figure 6.1 How well supported do families feel by healthcare professionals: working hours vs. out of hours

This first survey has explored the experiences of parents who perform a range of medical procedures for their children. The findings highlight two key themes in particular: i) the variability in experiences of training and ii) the emotional impact of families especially soon after coming home while they are still learning to provide the specialist care their children need. It is possible that some of the anxiety and stress families experience could be reduced by better training and support. The next survey will explore parents' experiences of training in more detail, focusing specifically on gastrostomy care which is a very common type of care. Hospital admissions for a gastrostomy surgery are also very short (around two days) so there can be limited time to train families before discharge. This next survey is informed by the themes identified in the first survey. The second

survey also uses the descriptions of training given by families in the first survey, to formulate more specific questions about the format and content of training families received, and to formulate questions on how training could be improved.

6.3 Survey 2: Parents' experiences of training and support and ideas for improvement

6.3.1 Methods

6.3.1.1 Survey Aims

The second survey had two distinct aims. The first was to understand the variability in parents' experiences of training and ongoing support for caring for their child's gastrostomy across a large sample of UK families. Parents was asked about what types of training and support they received, who they received training from, how confident they felt and anything that was missing from their training. They were also asked to describe their training in more detail in open text boxes. They were asked about which sources were helpful for ongoing support and whether they would like further training or support.

The second aim was to understand parents' recommendations for improving training and support. Parents were asked to rate how useful different formats of training are and to describe how their own training could have been improved. The stakeholder group supporting my research were keen to explore parents' views on the utility of educational videos: questions on the development of videos was therefore explored in this survey as a possible future avenue for my research. I developed an example video with one of my parent representatives which participants in the survey were asked to watch and

comment on. Participants were also asked to rate other potential topics for videos and for their preferences on where videos should be filmed and who should feature in them.

6.3.1.2 Survey development

The survey was developed in stages. In the initial exploratory stage, I reviewed the literature on gastrostomy training and consulted parent representatives, nurses and paediatricians from the community and hospital. The content of the survey was informed by findings from the first survey presented in this chapter, which highlighted family carers' feelings of being scared and unprepared, the variability in experiences of training and the emotional demands on families. The survey instrument was drafted, piloted and revised in consultation with parent representatives, children's nurses and paediatricians from the community, a paediatric gastrointestinal surgeon and a specialist surgical nurse. The team were asked to comment on the suitability of the questions, readability and length. Recruitment strategies were developed based on advice from our parent representatives, clinicians and charities.

6.3.1.3 Survey design

The second survey had a roughly even number of qualitative and quantitative questions and a larger sample of families. It was a fully mixed survey with the qualitative data intended to help support, illustrate and expand the quantitative data (Terry & Braun, 2017).

6.3.1.4 Sampling and recruitment

Participants were recruited through UK charities and local charities (see Appendix 6 for a list of the charities) and through our parent representatives who posted on closed Facebook groups which serve as support groups for families ('Tube Feeding your child in

the UK' which has 4105 members, and the 'Blended Diet UK' group which has 4200 members). The sample is best described as a convenience sample, however I purposely advertised through charities that support children with a range of different diagnoses and levels of complexity (e.g. Well Child, TOFS, Together for Short Lives) and sought to recruit family carers with different levels of experience (assessed as number of years since the child's gastrostomy surgery). It was clear from the survey question 'where did you hear about the survey' that some people also chose to share the survey with friends/family. The advertisement information informed participants that we were looking for family carers (e.g. parents) who cared for children with gastrostomies to complete a survey on their training and support needs. The exact wording varied slightly between the different charities and posts on Facebook groups. The first page of the survey gave some brief information about the survey.

The inclusion criteria were any parent or family carer who provides gastrostomy care at home to a child or young person aged under 25 years. By family carer, we included any unpaid carer (parent, relative, friend) who actively participates in caring for a child with a gastrostomy. To take part family carers needed to be at least 18 years old. Participants received a £10 voucher for taking part. The data were collected between July and September 2020. I aimed to recruit at least 100 participants to capture a broad range of experiences, including family carers new to gastrostomy care and some more experienced.

6.3.1.5 Ethics

All participants gave informed consent before taking part and consented for their data to be used in publications. I received ethical approval for the study from The Medical

Sciences Inter-Divisional Research Ethics Committee at the University of Oxford (Reference: R56623/RE004).

6.3.1.6 Analysis

Descriptive statistics were computed for all close-ended questions, using SPSS Statistics 25. Participants who did not complete the full survey were excluded (defined as viewing all pages of the survey and completing all the quantitative questions at a minimum). The open ended questions were coding in NVivo 12 using inductive content analysis, to group responses based on surface level of meaning (Elo & Kyngäs, 2008). Each meaningful statement (this ranged from phrases to sentences) were coded, and grouped into categories emerging from the data. These categories, or themes, were then summarised and illustrated with quotes from participants.

6.3.2 Results

6.3.2.1 Participants

One-hundred-and-forty-six participants fully completed the survey. 195 participants consented to take part and 250 responders viewed the first page. The majority of the 146 participants were mothers (91%). There was a range of ages of the children and time since initial gastrostomy surgery. The most common types of devices were gastrostomy buttons and percutaneous endoscopic gastrostomy (PEG) tubes. Table 6.2 gives more details about the participants.

Table 6.2 About the participants who completed the full survey on gastrostomy care

	N (%)
Relation to child	

Mother	133 (91%)
Father	8 (6%)
Other family member	5 (3%)
Age of participants' children (years)	
0-4	50 (34%)
5-9	38 (26%)
10-14	39 (27%)
15-19	18 (12%)
20-24	1 (1%)
Time since initial gastrostomy surgery (years)	
<1 year	15 (10%)
1-2	41 (28%)
3-4	27 (18%)
5+ years	63 (43%)
Type of gastrostomy device child has or previously had *	
PEG tube	73 (50%)
Gastrostomy button (MINI or Mic-Key)	115 (79%)
Another device (e.g. gastro-jejunostomy (GJ) tube)	23 (16%)

* Some children had more than one gastrostomy device, e.g. some children had a PEG tube initially which was later changed to a gastrostomy button.

6.3.2.2 Participants' descriptions of their training

Parents' experiences of training were hugely variable (see Box 6.2). Most parents described receiving some training in hospital but the nature and extent varied considerably. Descriptions of training as "*brief*" or "*basic*" were common. Some parents

felt unprepared and anxious: *"It was scary because we were worried about it getting caught/pulled and hurting or causing damage to our little boy. We didn't get much practice before being left to do it on our own so you are triple checking yourself and*

Box 6.2 Example quotes illustrating the variability of training

Training sometimes brief & basic:

- *"A brief 5 mins of basics, a leaflet and home. A few weeks later a Nutricia nurse came to the house to show us the pump."*
- "*We were admitted for the surgery and spent two further days in the ward after, received very basic training on the use of the peg and left feeling absolutely terrified about using it*!"
- *"Need much more training than 10 minutes in consultant's office!"*

Primarily self-taught with support from other parents:

- *"The official training - nothing good. Absolutely disastrous, vague, unsupportive. The unofficial training and the info I sought out for myself - clear, helpful videos from other parents, useful approach of gastrostomy nurse. Properly child-centric, helpful stuff."*

More community support needed:

- "*The community nursing team rely too much on the surgical nurse to do the training and then they just catch up with a chat following any training given at the bedside. This training is not detailed/long enough for those dealing with such a complex medical needs child."*

Thorough training and support received:

- *"Our daughter was in hospital long terms due to a range of factors. We were able to observe nurses undertaking feeds, using pump, giving medication. We were also given an information pack and work book to go through, and we were observed by nurses until confident and competent to do ourselves. We were given support in community… with regards to changing button, taking care of button, and annual refresher also. Received updates with regards to how much water to inflate balloon with, frequency of Ph testing etc."*

worrying did I do it right." Some parents described receiving further training at home by community nurses or representatives from a feeding company. Parents described

learning through other parents, often through Facebook groups: *"Also had amazing advice from other mums whose children have tubes who I found via Facebook groups - game changing stuff."*

The majority of parents reported receiving some training from their hospital team (n=115, 79%). A slightly smaller proportion received training from a Community Children's Nurse (CCN) (n=105, 72%). 35 participants (24%) mentioned training from another provider, most commonly a feeding company (e.g. Nutricia). 82 (56%) families had received training from both the hospital and CCN team, and 8 (5%) reported not receiving training from either the hospital team or a CCN team.

Table 6.3 shows the types of training parents received. The most common types of training were verbal information, demonstrations and supervised practice from a healthcare professional. Very few participants received any simulation practice (hands on practice with a doll/equipment), or watched instructional videos. A few of the parents that did receive simulation practice commented on the usefulness of this: *"Really useful being able to have a little play with a tube and practice using the clip etc. before having to do it for real."*

Table 6.3 Types of teaching/training received by parents

Types of teaching/training received	**N (%)**
Given information verbally by a healthcare professional	129 (88%)
Demonstrations by a healthcare professional	125 (86%)
Practised on my child supervised by a healthcare professional	113 (77%)
Given a written booklet	85 (58%)

Simulation practice (practiced with a doll or some equipment)	19 (13%)
Directed to a website for information	13 (9%)
Demonstrations by another family member	7 (5%)
Other	5 (3%)
Videos	3 (2%)

6.3.2.3 Confidence over time

Parents were asked how confident they felt caring for their child's gastrostomy in the first few weeks after surgery: 24 (16%) were not at all confident, 32 (22%) were slightly confident, 30 (21%) were moderately confident, 42 (29%) were mostly confident and 18 (12%) of parents said they were fully confident. At the time of the survey a majority (n=117, 80%) said they felt fully confident caring for their child's gastrostomy (n=117, 80%). The most common concern parents had were around hurting their child, caring for site after surgery, knowing "*what was normal*" in relation to the stoma site healing, worries about the tube coming out and problems such as blocked tubes or granulation:

"The first time I experienced this [granulomas] I thought my sons intestines were coming out! Nobody had ever mentioned it to me nor had I ever seen anything like it!"

It is not possible to say from the data whether the training participants received had improved over time. However, I did not find any evidence suggesting that participants' retrospective confidence ratings from the first week at home had changed over time, which may suggest that training has not changed or improved over time: 40% of participants with less than a year's experience rated themselves as 'not at all confident' or 'slightly confident' in the first week at home, compared to 38% of participants with

more than 5 years' experience. There was no statistically significant association between time since gastrostomy surgery and participants' ratings of confidence in the first week at home: $\chi^2(12, N=147) = 12.06$, $p = .44$. Again, this may suggest that training has not changed or improved over time.

However as expected, there was evidence that participants' ratings of their current confidence (at the time of the survey) did improve with more years' experience: 46% of participants with less than a years' experience rated themselves as fully confident caring for their child's gastrostomy, compared to 89% of participants with more than 5 years' experience. A chi-squared test revealed a significant association between current confidence ratings and number of years since gastrostomy surgery; $\chi^2(9, N=147) = 17.54$, $p = .04$.

6.3.2.4 Ongoing support and training

Participants were asked which sources were most helpful for ongoing support (see Table 6.4). Contacting your community nurses was rated as "very helpful" by a majority, with less than a quarter rating hospital teams as a very helpful source of support. Notably conversations with other parents was rated as "very helpful" by 56%, with a further 32% ratings support from parents as "quite helpful". Participants in the survey offered advice for other parents, including tips for managing their child's distress when changing a gastrostomy button.

Table 6.4 Sources of ongoing support: ratings of helpfulness

	Very helpful	**Quite helpful**	**Not very helpful**	**Not applicable**
Contacting your community nurse	90 (62%)	28 (19%)	13 (9%)	15 (10%)

Contacting your hospital team	34 (23%)	37 (25%)	38 (26%)	37 (25%)
Facebook groups	54 (37%)	67 (46%)	11 (8%)	14 (10%)
Conversations with other parents of children with similar needs	82 (56%)	47 (32%)	3 (2%)	14 (10%)
Written information booklets provided by a healthcare professional	28 (19%)	68 (47%)	32 (22%)	18 (12%)
NHS websites	15 (10%)	55 (38%)	52 (36%)	24 (16%)
Charities	25 (17%)	53 (36%)	19 (13%)	49 (34%)
Videos	29 (20%)	50 (34%)	17 (12%)	50 (34%)

Participants were asked, at the time of completing the survey, whether further training might be helpful to them: 14 (10%) said definitely yes to further training or support, 29 (20%) probably yes, 81 (55%) probably not and 21 (14%) definitely not. The most common request was help with managing problems. A number of participants wanted refresher training, or updates on the latest guidance: '*making sure bad habits have not crept in and that we are up-to-date with any changes in how things are done*'.

6.3.2.5 Participants' recommendations for improving training

Participants were asked which formats of training might be useful to other parents facing the challenge of caring for a child with a gastrostomy (see Table 6.5). Around three-quarters rated demonstrations and practice on my child supervised by a healthcare professional as extremely useful. Around two-thirds of participants felt that videos and simulation practice would be extremely or very useful. Participants felt that these additional forms of training would be a good addition to face-to-face training with a professional, but not a substitute: *"I think that the videos are good resources that parents can go back to however I think that face to face training is really important initially."*

Table 6.5 Which types of training might be helpful to other parents

	Extremely useful	Very useful	Moderately useful	Slightly useful	Not at all useful
Demonstrations by a healthcare professional	105 (72%)	33 (23%)	6 (4%)	2 (1%)	0 (0%)
Practised on my child supervised by a healthcare professional	110 (75%)	29 (20%)	5 (3%)	1 (1%)	1 (1%)
Written booklets	32 (22%)	39 (27%)	51 (35%)	19 (13%)	5 (3%)
Videos	40 (27%)	58 (40%)	29 (20%)	14 (10%)	5 (3%)
Simulation training (practicing with a doll or some equipment)	47 (32%)	45 (31%)	36 (25%)	10 (7%)	7 (5%)
Online training	18 (12%)	33 (23%)	47 (32%)	30 (21%)	17 (12%)
Group training with other parents	20 (14%)	34 (23%)	39 (27%)	31 (21%)	21 (14%)
Training by an experienced parents	15 (10%)	16 (11%)	32 (22%)	51 (35%)	32 (22%)

Participants had many suggestions for improving training. A common suggestion was more training and information about common problems including what to do if the button comes out, and requests for specific types of training, such as more hands on training. Some participants commented on the timing of training as they struggled to take information on board while in hospital: *"I think we should have had more [training] before his surgery and not while he was in theatre as we were so anxious I'm not sure how much we took in or how valuable doing it then was."* A few participants said they would

like to have been put in touch with other families: *"Opportunity to do group talks or training would be good. Nice way to meet other families and build a support network."*

6.3.2.6 Recommendations for developing training videos

Participants were shown a sample video showing a parent administering a bolus of water to their child. Participants liked how "real life" the video was: the child was wriggling during the procedure, it was done at home, it was relaxed and the mother was talking to the child throughout. One parent commented that: "*I've hated the teaching videos previously as they seem rather clinical but this was fantastic*." When asked where training videos should be filmed, 54 (37%) said at home, 4 (3%) said in hospital, and 88 (60%) said a mixture of both locations. 116 (80%) of participants wanted both healthcare professionals and parents to feature, 12 (18%) wanted just healthcare professionals and 8 (12%) wanted just parents. Participants rated different topics for videos: the vast majority were rated as 'very helpful' (see Appendix 9). More specific recommendations from participants for developing training videos are available in Appendix 9.

6.4 Discussion

6.4.1 Summary

The first survey presented in this chapter highlighted the emotional impact on families learning to care for a child who needs specialist healthcare at home and gave some indication of families' experiences of training and support. Family carers were often anxious and overwhelmed in the first few weeks of caring for their child at home and this was made worse by a lack of training and support: many were concerned about doing something wrong or worried about hurting their child. The second survey demonstrated substantial variability in families' experiences of training in relation to gastrostomy care, and also provided a range of suggestions from parents on how training and support could

be improved. Almost two in five family carers caring for children with gastrostomies reported feeling 'not at all confident' or only 'slightly confident' in the first week at home. With better training and support much of this could be avoided.

6.4.2 Recommendations for improving training and support

Family carers felt that demonstrations in hospital before going home were often too brief. Experiences of support in the community afterwards were highly variable. Consistent with other studies, ongoing learning and support via other parents and Facebook groups was common (Boland et al., 2017; McDonald et al., 2016). Family carers described various learning needs for gastrostomy care, particularly around managing problems, including issues with the stoma site and concerns about what to do if the tube comes out. Videos and simulation practice were rated as useful preparation by families, as an addition to face-to-face supervised practice with a healthcare professional. Family carers liked how real life the example video was, and rated nearly all suggested video topics as "very helpful". Troubleshooting topics were particularly valued. Participants wanted both parents and health professionals to feature in the videos, and for at least some of the videos to be filmed at home.

6.4.3 Implications for the design of services

Good quality training and support for family carers is recognised in the literature as key for optimising outcomes for children and preventing harm (Berman et al., 2017; Evans et al., 2010). The surveys in this chapter suggest that many families feel that the current training provided does not fully meet their needs, leaving many feeling scared and unprepared in the first few weeks caring for their child at home. Improving training may help to reduce readmissions, and also reduce the burden on families. Currently some

parents are falling through the gaps, which leaves the child at risk of complications, causes substantial stress and anxiety to parents and may lead to avoidable hospital admissions (potentially further surgery) as well as placing additional burden on overstretched community teams through increased callouts.

The data from the second survey on gastrostomy care suggests that parents may benefit from more training prior to taking their child home from hospital, and potentially competency checks before leaving hospital to ensure parents are prepared, not just for routine care but also for troubleshooting scenarios, which participants in the survey felt particularly unprepared for. Videos and other training materials could be made available to parents prior to the planned hospital admission. Parents may also benefit from more hands-on practice: this could be done through simulation practice (hands on practice with dolls and equipment) prior to practicing on your own child after they have had their surgery. Hospital admission for gastrostomy surgery are typically only two days, so there can be limited opportunity to practice on your own child, especially on busy wards. Training for parents needs to be made more of a priority, with more preparation and support prior to surgery and checks on competency to ensure parents are adequately prepared. Training resources should be co-designed with families and address their emotional needs (such as recognising parental anxiety and fears and discussing the potential impact of a gastrostomy on daily life) as well as the technical aspects of care. The implications for the design of services will be considered in more detail later in the thesis when I develop the training package.

6.4.4 Strengths and limitations

The two surveys have a number of strengths. Parents with different levels of experience responded to the surveys, from families who were very new to performing medical procedures for their children to families with more than 5 years' experience. Families were recruited through charities and Facebook support groups whose members come from across the UK: this suggests that the issues described by families in the survey are not unique to one region or service. Families were very engaged and many offered to help support the development of training videos and other resources.

One key weakness of the surveys is that we did not collect demographic data on the families so cannot tell the socio-economic, health literacy or ethnicity of families, or information about the children's diagnoses or their level of medical complexity. It is therefore impossible to know how selection bias played out in the surveys. We may have recruited families who are more engaged in their child's care or families who felt unprepared and sought help through Facebook groups and charities.

6.5 Conclusions

This chapter has highlighted the variability in experiences of training parents in the UK currently receive as well as the emotional impact on families which is intensified they are not given sufficient preparation and support. Although the literature suggested training and support for parents can be variable, this survey has clearly articulated the variability in experience with a relatively large sample of UK families. Critically the surveys have also provided a range of recommendations for how we might improve the current training and support.

This first section of my thesis has provided an in-depth understanding of the experiences of families who care for children with complex medical needs and the safety concerns of healthcare professionals who support them. The next section of my thesis will develop and test training interventions for parents new to gastrostomy care through online experiments testing factors shown to be effective for improving learning and memory in psychology. In the final two chapters I develop and evaluate a training package for parents caring for children with gastrostomies, informed by the recommendations of parents for improving training and support explored in this chapter and findings from the experiments in Chapters 7-9.

Chapter 7 Schema- and retrieval-enhanced memory for learning medical information

7.1 Introduction

The previous few chapters of my thesis have provided an overview of the clinical issues relating to care at home for children with complex medical needs. This next stage of my thesis develops and tests training interventions for parents caring for children with gastrostomies. The next three chapters use online experiments to evaluate the impact of different types of training materials on learning and memory. In the final part of my thesis I implement and evaluate a training intervention with families caring for children with gastrostomies.

7.1.1 Online experiments as a means of developing and testing training interventions

Conducting online experiments with the general public (who have little or no knowledge of gastrostomies) offers a way of testing the effectiveness of potential training interventions. Testing training interventions in the real-world setting is expensive, time-consuming and logistically complex: in order to recruit an adequate sample size of parents caring for children with gastrostomies a multi-site study would be required and would take several years to complete (only around 80 children a year have surgery for a gastrostomy at the JR hospital which serves as a specialist centre for a population of several million across several counties). Online experiments provide a relatively inexpensive and quick means of assessing the impact of different training interventions on learning and memory, offering a "proof-of-concept" before real-world testing. The studies presented in the next three chapters test ways to improve the "information giving" stage of training for parents, by leveraging findings from cognitive psychology (as explored in Chapter 2 of my thesis). The experiments test whether tools for enhancing

learning and memory shown to be effective in experimental studies from the field of cognitive psychology can enhance the learning of complex medical information on gastrostomy care. In the final section of my thesis I use the findings from these experiments to inform the development of a real-world intervention to train and support parents caring for children with gastrostomies.

7.1.2 The "information giving" stage of training

A crucial part of learning to perform complex medical procedures is understanding and remembering technical medical information (i.e. learning and memory). As discussed in Chapter 2, encoding information is the foundation for the later development of motor and cognitive skills. For example, parents learning to care for a child with a gastrostomy have to learn how to care for the stoma site (where the tube enters the stomach), the steps involved in administering feeds and medications, and what signs and symptoms to look out for to indicate there is a problem. Parents caring for children with gastrostomies typically receive initial information in the form of written booklets produced by healthcare providers, verbal information from healthcare professionals and sometimes online information on websites. Poor comprehension and memory for this critical information can put the child at risk of harm, such as wound infections from not cleaning the stoma site properly. Several studies have shown concerning gaps in the knowledge of parents caring for children with gastrostomies including the study presented in Chapter 3 of my thesis (Evans et al., 2012, 2010; Page, Nawaz, Haden, Vincent, & Lee, 2019). It is vital that parents can understand and remember the information provided to them, and accurately track what they know and do not know so they can seek help when needed.

This study tests ways to improve the "information giving" stage of training based on findings from cognitive psychology. The two concepts utilised in this study, with the aim of improving memory for new information, are schemas and recall practice. We chose schemas and retrieval practice because they are both powerful and inexpensive tools for improving learning, and have been widely recommended to educational practitioners (Roediger & Pyc, 2012; Weinstein et al., 2018) and for training healthcare professionals (Regehr & Norman, 1996). I therefore tested the effectiveness of schema and retrieval-enhanced training materials in improving initial retention of information about feeding tube care.

7.1.3 Schemas

Schemas are fundamental to how we organise and make sense of new information, and integrate this with our existing knowledge. Schemas are cognitive structures consisting of connected items of knowledge, which provide a framework for the organisation and incorporation of new information (Anderson & Pearson, 1984; Bartlett, 1932; Greve et al., 2018; Hasher & Alba, 1983). While recent work has begun to explore the neural and computational basis of schema-enhanced memory (Alonso, van der Meij, Tse, & Genzel, 2020; Ghosh & Gilboa, 2014; Van Kesteren, Ruiter, Ferná Ndez, & Henson, 2012), the present study builds on foundational work showing the impact of schemas on understanding and retaining new information (Alba & Hasher, 1983; Bransford & Johnson, 1972). This work has shown in particular that to the degree that learners form links among new pieces of information, and link these to their existing knowledge, they create multiple routes for retrieving the information that facilitate retrieval in the future (Bradshaw & Anderson, 1982). Schemas are also critical for applying information to new scenarios based on similar scenarios previously encountered, which is essential for

problem solving. I hypothesised that enhancing training materials to promote the generation of strong schemas will improve memory for the information. In the schema-enhanced conditions of this study, I therefore presented key themes at the start of the study information, such as infection control and treating the gastrostomy stoma site like a wound, and made links back to these core concepts throughout the information. I anticipated that this would help participants to link the information presented and aid integration with their existing knowledge.

7.1.4 Retrieval practice

The second learning tool utilised in this study is retrieval practice. Retrieval practice, actively retrieving information from our long-term memory, has a dual benefit: it boosts memory for information accurately recalled and also helps the learner track what they know and do not know, which leads to more targeted study (Roediger & Karpicke, 2006a). Retrieval practice, which is also referred to as the testing effect, is the finding that tests requiring learners to recall previously-studied information can strengthen their memory for the information retrieved, which improves subsequent memory performance (Roediger & Karpicke, 2006b; Rowland, 2014). The effects of testing (retrieval practice) during learning on long-term memory are consistent and large, both in the lab and in real-world settings such as school classrooms (Roediger & Karpicke, 2006b). However some recent studies have explored boundary conditions of the testing effect which are relevant to applied settings, e.g. the effect may only hold when the delayed memory test is not very closely related to the questions used in the retrieval practice (Wooldridge, Bugg, McDaniel, & Liu, 2014) or that the effect may even disappear when the complexity of the learning materials increases (van Gog & Sweller, 2015). The other benefit of recall is its metacognitive implications. Retrieval practice can give you feedback on the gaps in

your knowledge, which is particularly useful when you re-study the information, as you can do so in a more targeted way (Karpicke & Grimaldi, 2012; Nelson, Dunlosky, Graf, & Narens, 1994). This effect has also been shown in applied contexts, for example, with participants who self-tested and evaluated their learning of information about diabetes self-management performing better in a final test (Rawson, O'Neil, & Dunlosky, 2011). I hypothesised that enhancing training materials to include a recall-based task with the opportunity for targeted restudy of the information afterwards would improve memory for the information, when compared against restudy only.

7.1.5 This study

The experiment thus evaluated whether schema-enhanced training and retrieval-enhanced training would improve learning and memory for information about a complex medical task (gastrostomy care), using a between-participants design. Participants in the baseline group were asked to read an existing information booklet on gastrostomy care from the NHS, then had the opportunity to re-read it in a second session 2-4 days later, and finally were tested on their memory for the information 6-8 days after the first session. Participants in the schema-enhanced condition followed the same regime, but with a longer version of the booklet that included additional conceptual linking information. Two further groups also studied either the basic or schema-enhanced booklet, but in addition were given retrieval practice during the second session, prior to the opportunity to restudy the relevant version of the booklet, with memory again tested in a final session. I predicted that both schema-enhancement and retrieval practice would improve learning, reflected in increased memory performance in the final test session. The factorial design additionally allowed us to assess possible interactions between the two manipulations.

7.1.6 Aim of the study

The aim of this experiment was to determine whether schema-enhanced training and retrieval-enhanced training improve memory for information about a complex medical task (gastrostomy care) compared to studying and re-reading an existing NHS information booklet on gastrostomy care.

7.2 Method

7.2.1 Participants

The experiment consisted of three sessions. On day 1 participants completed the first learning session, on day 2-4 they completed the second learning session, and on day 6-8 they completed the final session which was a cued-recall memory test. The experiment had a between-participants factorial design with two between-group factors (schema and retrieval) each with two levels. Box 7.1 summaries the design.

Participants were randomly assigned to either the control or schema-enhanced condition in Session 1 using the randomiser function in Qualtrics. The randomisation function used ensured an even number of participants were randomised to the two groups (however there was an uneven drop-out rate during the session between the two groups which resulted in an unequal-sized groups in the analysis).

Participants who fully completed the first session were then randomised to receive the re-read or retrieval-enhanced condition for Session 2. Half of the participants who studied the schema-enhanced materials were randomised to re-read the materials, and half to complete the retrieval activity. Likewise half of the participants who studied the control booklet in Session 1 were randomised to re-read the control materials and half to complete a retrieval activity. There were therefore four groups in the design: schema and

re-read, schema and retrieval, control and re-read and control and retrieval. This second randomisation stage was done manually using alternate allocation on an Excel spreadsheet (randomisation could not be done within Qualtrics due to limitations with the functionality of the software for multi-stage studies). All participants received the same cued-recall test in Session 3.

Box 7.1 : Design of study

Session 1

Participants randomised to study either:

1. i) NHS information booklet (control booklet)
2. ii) Schema-enhanced version of NHS information booklet

Session 2

Participants randomised a second time to either:

1. i) Re-read the information booklet they studied previously (either control booklet or schema-enhanced version)
2. ii) Complete a retrieval intervention on the information they received in Session 1 and then re-study this information

The design therefore has four groups:

	Control booklet	*Schema-enhanced*
Re-read	Control + re-read	Schema + re-read
Retrieval + re-read	Control + retrieval	Schema + retrieval

Session 3

All participants receive the same cued free recall test

My pre-registered sample size was 100 participants. I calculated (using G*Power) that I would need a minimum sample size of 90 participants (45 in the schema-enhanced group and 45 in the retrieval-enhanced group) based on the power to detect a medium effect size of 0.6 for the two main effects (schema-enhancement and retrieval-enhancement)

using an alpha value of 0.05 and power (beta) of 0.8. In this experiment I was primarily interested in whether the schema-enhancement or retrieval-enhanced training would improve memory for the information studied and therefore planned to look at the main effects of the schema-enhancement and retrieval-enhancement, considering each effect separately. Medium effect sizes are consistent with effect sizes reported in the literature, and large enough to be meaningful in the applied context of improving training for parents. I did not have a basis for what to expect from the interaction between the two manipulations so this was not included in the power analysis. The primary interest was in whether the schema or retrieval-enhancements would be beneficial to learning. A key guiding principle for the power analysis was that we were only interested in relatively large effect sizes which would be large enough to be meaningful in the applied context of improving training for parents.

In total, 141 participants were initially recruited via the online platform Prolific Academic. Participants who did not complete the full session were not invited to take part in the next session. In addition, participants who spent less than 3 minutes studying the information in Session 1 (in either the control or schema condition) or less than 5 seconds studying any individual page of the control and schema information were excluded from the study and were not invited to take part in Sessions 2 and 3. Any participants who did not complete Session 2 in the required time window (two days) were not invited to take part in the final session. A flowchart in Appendix 10 shows the participant drop-out rate by session and the numbers of participants excluded for poor compliance. After these exclusions, my final sample comprised 100 adults of typical parent age (aged between 21 and 50). There were 28 participants in the control and re-read group, 25 in the control and retrieval group, 25 in the schema and re-read group and 22 in the schema and

retrieval group. The unequal group sizes were a result of drop-out rates varying between groups.

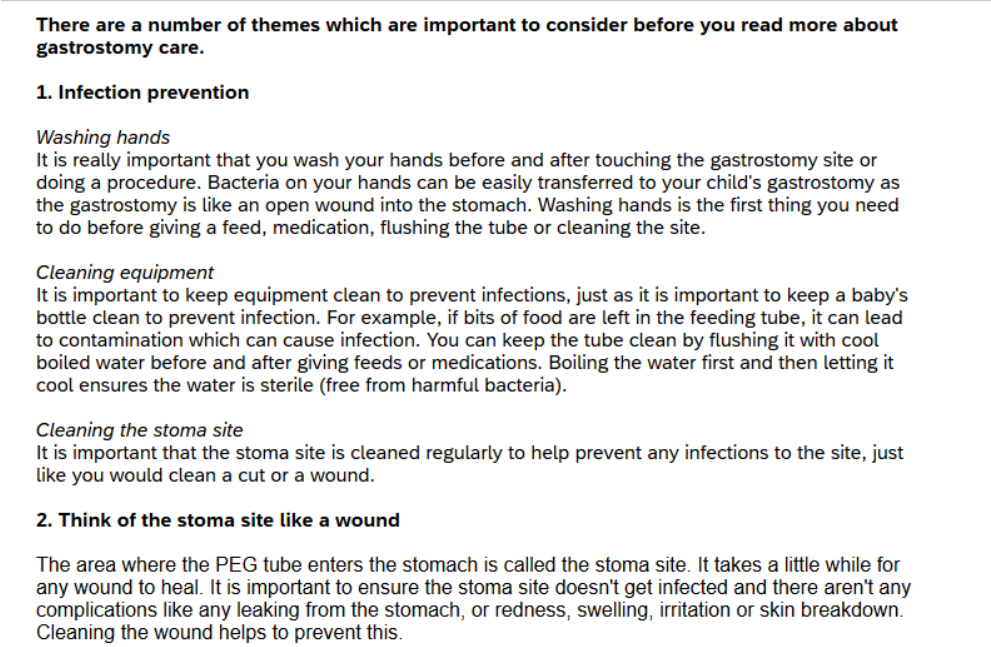
The mean age of participants was 35 years (*SD* = 7.5). The sample was 64% female, 72% had degree level qualifications and 28% had school and college-level qualifications. All participants were from the United Kingdom and fluent in English. All participants self-certified that they did not work in healthcare, and had no previous experience caring for somebody with a feeding tube, and therefore did not have extensive prior knowledge of feeding tube care. Participants completed the study online, remotely and were paid for their time via Prolific. All participants gave informed consent before taking part. I applied for and received ethical approval for the study from The Medical Sciences Inter-Divisional Research Ethics Committee at Oxford University (Study reference: R61895/RE001).

7.2.2 Design

The experiment compared training-as-usual for gastrostomy care (reading an NHS information booklet) with schema and recall-enhanced training in a factorial 2-by-2 design. In the schema-enhanced condition, the information booklet was augmented by adding short descriptions of core themes to the start of each section of the booklet, and elaborations relating information to these core themes throughout the text. Retrieval practice was included as a second training session (2-4 days after the first) and compared against re-read only. All participants received a cued recall test on day 6-8. The study was pre-registered through the Open Science Framework (https://osf.io/ye8f5).

7.2.3 Materials

Session 1 consisted of information from an existing NHS booklet on gastrostomy care (care of a PEG)[1]. The booklet included information on routine care and troubleshooting. The schema-enhanced version of the information was augmented with additional text, which explicitly articulated key themes, such as infection control and treating the stoma site like a wound. The themes were clearly described at the beginning of the two sections (routine care and troubleshooting) and clear links to the themes were added throughout the information (see Figure 7.1 for an example). The themes were developed based on discussions with a paediatrician and paediatric surgeon. The schema-enhanced condition was 66% longer in word count (2718 words vs. 1641 words for the original NHS booklet).



There are a number of themes which are important to consider before you read more about gastrostomy care.

1. Infection prevention

Washing hands
It is really important that you wash your hands before and after touching the gastrostomy site or doing a procedure. Bacteria on your hands can be easily transferred to your child's gastrostomy as the gastrostomy is like an open wound into the stomach. Washing hands is the first thing you need to do before giving a feed, medication, flushing the tube or cleaning the site.

Cleaning equipment
It is important to keep equipment clean to prevent infections, just as it is important to keep a baby's bottle clean to prevent infection. For example, if bits of food are left in the feeding tube, it can lead to contamination which can cause infection. You can keep the tube clean by flushing it with cool boiled water before and after giving feeds or medications. Boiling the water first and then letting it cool ensures the water is sterile (free from harmful bacteria).

Cleaning the stoma site
It is important that the stoma site is cleaned regularly to help prevent any infections to the site, just like you would clean a cut or a wound.

2. Think of the stoma site like a wound

The area where the PEG tube enters the stomach is called the stoma site. It takes a little while for any wound to heal. It is important to ensure the stoma site doesn't get infected and there aren't any complications like any leaking from the stomach, or redness, swelling, irritation or skin breakdown. Cleaning the wound helps to prevent this.

Figure 7.1 An example of the schema-rich information presented at the start of Session 1 to participants in the schema-enhanced condition. Additional references were added throughout the text to refer back to these core themes or schemas presented at the start.

[1] https://www.patientsafetyoxford.org/clinical-safety-programmes/previous-programmes/paediatric-gastrostomy/overview/paediatric-gastrostomy-resources/booklets-for-parents/

7.2.4 Procedure

7.2.4.1 Session 1

Participants were instructed to switch off their phone/email/music before they started the study. They were informed that the study consisted of three sessions. Firstly, they completed demographic questions (age, gender and education) and rated how familiar they were with a list of 15 medical terms and 15 parts of the body on a 5-point Likert scale from 'completely unfamiliar' to 'very familiar' (this was not intended to be an assessment of health literacy, but rather as a means of familiarising participants with a list of words which they would be tested on in Session 3 as a means of assessing general differences in memory performance, compliance and attention to be used as a covariate in the analysis). Next participants were randomised to receive either the schema-enhanced or the control version of the gastrostomy information. They were instructed to read the information carefully and told explicitly that they would not be invited to take part in Sessions 2 and 3 of this study if their data indicated that they had not followed the instructions to read the information carefully. At the end of the session, participants rated three questions on 7-point Likert scales: i) how easy the information was to understand (from "very hard to understand" to "very easy to understand"), ii) the amount of information given (from "far too little information" to "far too much information") and iii) how confident they were that they would remember the information in a week's time (from "not at all confident" to "very confident").

7.2.4.2 Session 2

In the second session, participants were randomised to receive either the retrieval-enhanced or re-read condition. In the retrieval-enhanced condition, participants

completed four retrieval activities. They were given the following instruction: “Imagine you have to explain what you have learnt so far about gastrostomies to somebody else (e.g. another parent, your partner or a nurse). Please think through what you would say, and make notes in the box below. These can be bullet points or phrases.” Figure 7.2 shows an example of what participants in the retrieval practice condition did in Session 2. There were four of these boxes that targeted the four major topics in the information (basic care of a gastrostomy, weekly care and flushing, giving feeds and medication, and troubleshooting), each with a few prompt questions intended to get participants started. Participants were asked to re-read the information from the relevant subsection of the gastrostomy information from Session 1 in between each retrieval task. The retrieval task was designed to be open-ended since the testing effect has been found to be stronger when the retrieval activity is free-recall based rather than a recognition test (Rawson & Zamary, 2019). The decision to include a box for participants to make notes was informed by studies which suggest that writing down key information such as keywords can improve metacognitive monitoring, which we hypothesised would help participants to restudy the information in a targeted manner (Thiede et al., 2003).

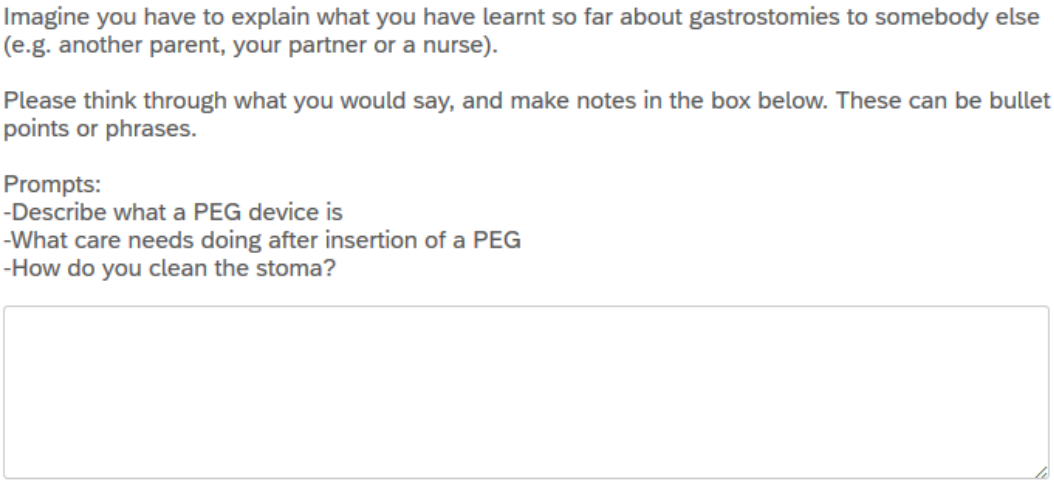


Figure 7.2 Illustration of the recall activity participants did in Session 2 in the retrieval condition. Participants completed 4 recall task corresponding to different sections of the study information.

In the re-read condition participants were instructed to re-study the information on gastrostomy care from the first session carefully. They were given a recommended study time of 20-30 minutes.

At the end of the session, participants in all conditions were asked to rate the amount of information given (from “far too little information” to “far too much information”) and how confident they were that they would remember the information in the final session (from “not at all confident” to “very confident”)

7.2.4.3 Session 3

The final session comprised three separate tests of participants’ memory of material presented in the previous sessions. The first of the three tests was our primary measure of learning and the focus of our pre-registered predictions and analyses: Participants were asked 16 cued-recall questions testing their memory and understanding of the information they had studied in Sessions 1 and 2, and additionally were asked to rate their confidence in their answer to each question on a sliding scale from 0 (not at all

confident) to 100 (fully confident). Example questions included “What should you use to clean the stoma site after the site has healed” and “Name four things you could try if the tube became blocked”. In the case of questions requiring multiple answers, as in the second example, points were awarded for each correct answer. Near-synonyms were marked as correct. Answers which were correct but not specific enough were awarded part marks. For example, for the question “what does venting refer to?”, the correct answer from the study materials was “expelling excess air or wind from the abdomen.” Vague answers that mentioned air or wind were awarded ½ mark. Answering referring to releasing air or wind from the stomach were awarded 1 mark. The maximum total score was 44. The free-recall test was scored by a researcher blind to which condition participants were in.

The second test was intended as a more exploratory assessment of whether differences in memory across groups would also (or more clearly) be apparent in more open-ended, problem-based questions. Participants were asked to read seven short scenarios and indicate for each how they would respond. An example question included “You have noticed that there is a red, raised area that is possibly bleeding developing at the stoma site, what would you do?” These were all scenarios that parents with children with gastrostomies may have to deal with. However, once the data were collected, participants’ answers were sufficiently varied that I felt unable to develop a rigorous scoring system that we had confidence in, and therefore the results of this test are not reported or discussed further below.

The third test provided a control measure that we intended would increase the power of our between-participant design. We reasoned that substantial between-participant

variation in memory performance might reflect individual differences in memory performance, attention and compliance, independent of our schema and retrieval practice manipulations. To estimate these nuisance effects, we assessed participants' memory of the medical terms (correct recognition of 10 of the 15 terms in the original list, with 5 distractors) and parts of the body (number correctly freely recalled out of a maximum of 15) presented to them as a familiarity rating task in Session 1. Participants were awarded 1 mark for each correctly recalled body part in the free recall test, and 1 point for each medical term they recognised as on the original list, with 1 point deducted for each of the distractors they wrongly indicated was on the original list. The summed score in these recognition and recall tests was then used as a covariate assessing general memory performance in our main analyses of memory for the key feeding tube booklet material. By including this covariate in the main analysis I hoped to increase the power of the between-participant design by accounting for some of the variability caused by differences in performance, attention and compliance. The choice of medical terms as part of the task was purely to make the task appear relevant to participants: the covariate was not an assessment of health literacy.

7.3 Results

7.3.1 Performance in the cued-recall test

My key pre-registered analysis focused on Session 3 memory performance in the 16-item cued-recall test for booklet material. Scores in this test ranged from 7 – 36 (*M* = 23.2, *SD* = 6.8) across participants, out of a maximum score of 44. Directly counter to my original predictions, the mean score was numerically highest for participants in the group receiving training-as-usual, the control booklet with re-reading condition (*M* = 24.8, *SD* =

6.8), followed by the schema-enhanced booklet with retrieval practice condition (*M* = 24.2, *SD* = 7.9) and the control booklet with retrieval practice condition (*M* = 23.3, *SD* = 6.0). Performance was lowest for participants in the schema-enhanced booklet with re-reading condition (*M* = 20.4, *SD* = 6.1) (see Figure 7.3).

To evaluate these cued-recall scores, I ran a 2 x 2 analysis of variance (ANCOVA), with schema-enhancement (control booklet vs. schema-enhanced) and retrieval-enhancement (retrieval practice vs. re-read) as factors, and with general memory performance included as a covariate to account for between-participant variance in memory ability and task compliance (for which scores ranged from 1 to 20 across participants, *M* = 11.3, *SD* = 3.6, with no significant differences across conditions). As per my pre-registered analysis plan, I did not include Session 1 study time as a covariate in this analysis because, as discussed below, preliminary analysis revealed that there were differences in study time between the schema and control booklet conditions.

The analysis revealed no significant main effect of schema-enhancement (schema version: *M* = 22.2, *SD* = 7.2; vs. control *M* = 24.1, *SD* = 6.4), $F(1,95) = 2.80$, $p = .10$, $\eta p^2 = .03$, no significant main effect of retrieval-enhancement (retrieval practice: *M* = 23.7, *SD* = 6.9, vs. re-read: *M* = 22.7, *SD* = 6.8), $F < 1$. The effect of the memory covariate was significant, $F(1,95) = 8.40$, $p = .005$, $\eta p^2 = .08$). There was a significant interaction effect on performance in the cued free recall test; $F(1,95) = 7.06$, $p = .009$, $\eta p^2 = .07$. Figure 7.3 shows the cued-free recall means for each condition. The values shown are the estimated marginal means for the cued-free recall test which take into account the effect of the covariate. Without the memory covariate included in the analysis, there was still a

significant interaction effect on performance in the cued free recall test although the effect size was smaller; F(1,96) = 3.94, p = .05, ηp^2 = .04.

Follow-up pairwise comparisons using Bonferroni corrections with general memory performance as a covariate indicated there was a significant difference between schema + retrieval (M = 24.4, SD = 1.38) and schema + re-read conditions (M = 19.7, SD = 1.31); F(1,95) = 6.10, p = .015. There was also a significant difference between control + re-read (M = 25.4, SD = 1.24) and schema + re-read (M = 19.7, SD = 1.31); F(1,95) = 9.77, p = .002.

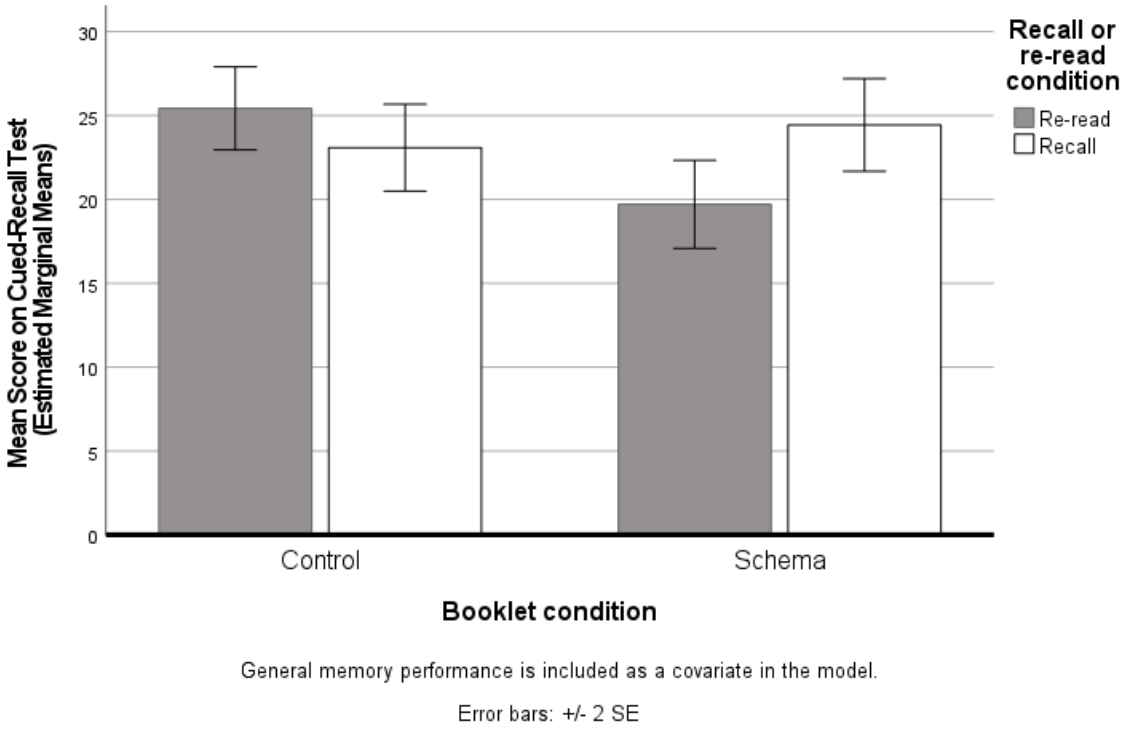


Figure 7.3 Cued-free recall scores for each condition by booklet condition (control vs. schema-enhanced) and re-read vs. recall.

I also conducted further analyses using negative scoring for dangerous answers in the cued-free recall test, to differentiate between responses left blank or answers such as "I would see help from a nurse", from clinically dangerous answers such as replacing a PEG device yourself (as specified as exploratory analyses in my pre-registration). The patterns

of objective memory performance were the same as to the primary outcome measure. There was no main effect of schema or retrieval-enhancement on scores in the cued free recall test with negative scoring taken into account, and there was a significant interaction between schema and recall-enhancement. Further details on these analyses are given in Appendix 11.

In summary, analysis of our critical measure of learning of medical information did not confirm the predicted pattern: numerically, the highest memory scores were in the control and re-read condition followed by schema and retrieval and then control and retrieval. The lowest memory score was in the schema and re-read condition. Schema-enhancement was unexpectedly harmful to learning, but performance was rescued by the retrieval task. The retrieval practice itself did not improve learning of the control booklet.

7.3.2 Confidence ratings on the cued-recall test

The patterns of objective memory performance described above were largely reflected in our secondary outcome measure of participants' subjectively rated confidence in their cued-recall answers (see Figure 7.4). Mean confidence ratings (out of 100) ranged from 10 – 89 across participants (*M* = 55.3, *SD* = 17.9). Confidence ratings were highest for participants in the schema + retrieval condition (*M* = 62.4, *SD* = 18.3), followed by control + re-read (*M* = 56.7, *SD* = 18.7), control + retrieval (*M* = 55.9, *SD* = 15.7) and lowest in the schema + re-read condition (*M* = 47.5, *SD* = 16.9).

In order to assess whether there were any significant differences in mean confidence, I ran a 2 x 2 analysis of variance (ANCOVA), with schema-enhancement (control booklet vs. schema-enhanced) and retrieval-enhancement (retrieval-enhanced vs. re-read) as

independent variables, mean confidence rating in the cued free-retrieval task as the dependent variable and general memory performance included as a covariate. There was no significant main effect of schema-enhancement (M = 54.5, SD = 18.9) vs. control (M = 56.3, SD = 17.2) on mean confidence in the cued free recall test; $F < 1$. There was a significant main effect of retrieval-enhancement (M = 59.0, SD = 17.1) vs. re-read (M = 52.3, SD = 18.3) on mean confidence in the cued free recall test; F(1,95) = 4.52, p = .036, ηp^2 = .05. There was a significant effect of the general memory covariate which was included in this model; F(1,95) = 6.01, p = .016, ηp^2 = .06.

There was a significant interaction effect on mean confidence in the cued free recall test as can be seen in Figure 7.4; $F($1,95) = 7.79, p = .006, ηp^2 = .08. Follow-up pairwise comparisons using Bonferroni corrections with the general memory covariate included, indicated there was a significant difference between schema + retrieval (M = 63.0, SD = 3.6) and schema + re-read (M = 46.0, SD = 3.45); F(1,95) = 11.4, p = .001. There was also a significant difference between control + re-read (M = 58.0, SD = 3.26) and schema + re-read (M = 46.0, SD = 3.45); F(1,95) = 6.20, p = .015.

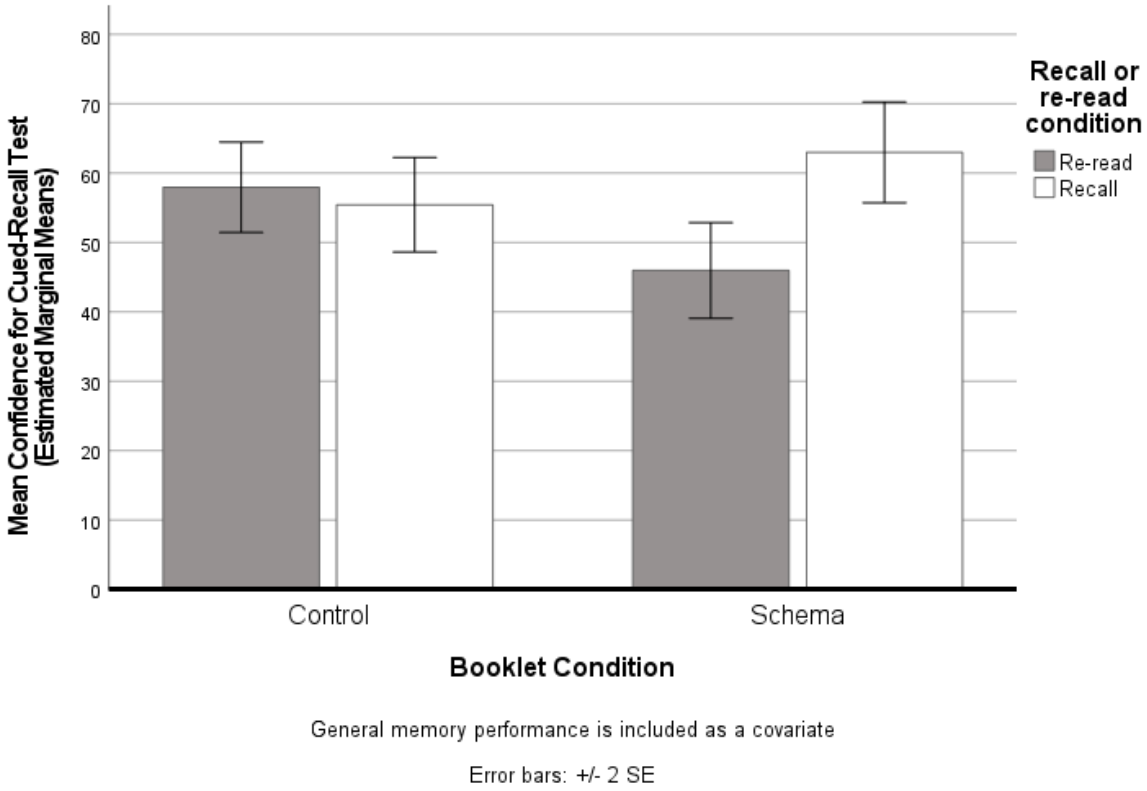


Figure 7.4 Mean confidence ratings on the cued-free recall task by booklet condition (control vs. schema-enhanced) and re-read vs. recall

In summary, analysis of our confidence ratings did not confirm the predicted pattern: numerically, the highest memory scores were in the schema and retrieval condition, followed by control and re-read and control and retrieval. The lowest memory score was in the schema and re-read condition. Schema-enhancement was unexpectedly harmful to confidence ratings, but performance was rescued by the retrieval task. The retrieval practice itself did not significantly improve learning of the control booklet. Given these surprising results, subsequent analyses focus on participants' memory ratings in Session 1 and the time they spent studying, to understand what was driving the differences in memory performance between the groups.

7.3.3 Participant ratings of the learning materials

Participants were asked three questions (as manipulation checks) at the end of Sessions 1 and 2: ratings of the amount of information, how easy the information was to

understand, and their confidence remembering the information in a weeks' time. Understanding differences in these responses can help explore possible reasons for the differences in performance in the cued-recall test.

7.3.3.1 Amount of information

Participants rated the amount of information provided on a 7-point scale, ranging from 1 ("far too little information") to 7 ("far too much information"). Although the schema condition was 66% longer in word count (1641 words in the control condition and 2718 words in the schema condition), there were no significant differences between the schema-enhanced and control booklet in participants' ratings of the amount of information in the study materials: $t(98) = 0.42$, $p = .67$. The mean rating for amount of information was slightly higher for the control booklet ($M = 4.75$, $SD = 0.9$) than for the schema version ($M = 4.68$, $SD = 0.8$). Participants did not perceive the schema materials to be too long.

7.3.3.2 Ease of understanding of the materials

Participants rated the ease of understanding of the medical information on a 7-point scale, ranging from 1 ("very hard") to 7 ("very easy"). Ratings at the end of Session 1 were significantly higher for participants who were given the schema-enhanced booklet information ($M = 5.2$, $SD = 1.4$) than the original, control version ($M = 4.2$, $SD = 1.7$), $t(98) = -2.97$ $p = .004$. The schema-enhanced material was also rated easier to understand at the end of Session 2 ($M = 5.1$, $SD = 1.3$, vs. $M = 4.4$, $SD = 1.7$ for the control booklet), where an ANOVA on mean ratings across the 2x2 factorial design revealed a significant main effect of schema-enhanced vs. control materials, $F(1,96) = 5.12$, $p = .03$, $\eta p^2 = .05$.

7.3.3.3 Judgements of learning

Participants gave judgements of learning, rating their confidence that they would remember the information in the final test, on a scale from 1 ("not at all confident") to 7 ("very confident"). At the end of Session 1, judgements of learning were numerically higher for participants given the schema-enhanced material (M = 3.6, SD = 1.2) than the control version (M = 3.2, SD = 1.4), but the difference was not statistically reliable, t(98) = -1.62, p = .11.

However there was a significant difference in participants' ratings at the end of Session 2 for both the schema enhancements vs. control and retrieval vs. re-read. A 2x2 ANOVA revealed a significant main effect of schema-enhancement, $F(1,96) = 4.85$, p = .03, ηp^2 = .05, with participants given the schema-enhanced material expressing higher judgements of learning (M = 3.7, SD = 1.4) than those given the control version (M = 3.2, SD = 1.3). In contrast, a main effect of retrieval-enhancement, F(1,96) = 6.30, p = .02, ηp^2 = .06, revealed that participants given retrieval practice were significantly less sure they would remember the information in the final test (M = 3.1, SD = 1.3) than participants in the re-read condition (M = 3.8, SD = 1.4). There was no significant interaction between schema and recall on judgements of learning, (F<1).

These participant ratings indicate that the ineffectiveness of schema-enhancement to improve final memory performance was not because the schema-enhanced information was confusing rather than helpful: although the schema-enhanced version was longer, participants did not rate the schema-enhanced material as too long, and in fact rated it as more comprehensible and more likely to be remembered at the final test.

7.3.4 Time taken to study the materials

I purposely did not control for study time in this experiment: It would be unrealistic to control study time in the applied context of parents studying information on feeding tube care, and we were interested in evaluating our intervention with realistic (lack of) constraints on individuals' learning behaviours. For example, we might expect parents' judgements of their learning will affect the time they spent studying the information (Nelson et al., 1994; Thiede et al., 2003). I therefore conducted analyses of differences in study time across groups.

7.3.4.1 Session 1 Reading time

The mean study time for Session 1 for the schema-enhanced material was 16% longer than the mean for the control condition: 9.2 minutes (*SD* = 4.1) vs. 7.9 minutes (*SD* = 3.4). This is proportionally much less than the 66% longer word count of the schema-enhanced material, as reflected in significantly longer mean reading time per word for participants given the control material (*M* = 0.29 seconds, *SD* = 0.13) than participants given the schema-enhanced information (*M* = 0.20, *SD* = 0.09); $t(98) = 3.83$, $p < .001$.

7.3.4.2 Session 2: Time spent re-reading the information

After completing the retrieval activity (which took participants a mean of 14.4 minutes, *SD* = 7.4), participants had the opportunity to re-study the original information. Participants in the re-read condition simply re-studied the information, without doing the retrieval task first. Time spent restudying the information was longest in the control and re-read group, (*M* = 8.1, *SD* = 5.9), followed by the schema and re-read condition (*M* = 8.0, *SD* = 6.3) and then the control and retrieval condition (*M* = 5.6, *SD* = 3.6). Time spent restudying the information was shortest in the schema and retrieval condition (*M* = 5.2,

SD = 2.7): Participants spent significantly longer re-reading the information in the re-read condition (*M* = 8.0 minutes, *SD* = 6.0) than in the retrieval condition (*M* = 5.4, *SD* = 3.2); $F(1,96) = 6.92$, $p = .01$, $\eta p^2 = .07$. This is surprising since if retrieval practice helps identify over-confidence or gaps in knowledge, we might expect longer reading times, especially in the schema and retrieval group. Contrary to expectations, the retrieval condition did not incentivise participants to spend longer re-reading the information although the retrieval practice did reduce their confidence in the judgement of learnings. It is however possible participants read the information in a more targeted manner.

There was no significant effect of the schema-enhancement on Session 2 reading time ($F<1$), despite the schema booklet being 66% longer in word count, nor a significant interaction between schema-enhancement and retrieval-enhancement ($F<1$). The mean reading time per word was significantly longer in the control condition (*M* = 0.25 seconds, *SD* = 0.18) than in the schema-enhanced condition (*M* = 0.15, *SD* = 0.11); $F(1,96) = 11.74$, $p = .01$, $\eta p^2 = .11$.

7.4 Discussion

7.4.1 Summary

This experiment evaluated whether schema-enhanced learning material and retrieval practice would improve naïve participants' retention of information about a complex medical task (gastrostomy care). Contrary to my expectations, the interventions did not significantly improve participants' cued-recall performance relative to training-as-usual (an existing NHS booklet, with opportunity to re-study), nor did it increase their confidence in their answers. Of particular surprise, participants given the schema-enhanced material and opportunity to re-study actually performed significantly worse

than other groups, with performance rescued back to baseline levels when retrieval practice was included in the second session. The manipulation checks at the end of Sessions 1 and 2 suggest that participants found the schema information easier to understand, spent less time per word reading the information and were more confident they would do well in the test a week later. The data suggest that schemas in the absence of retrieval practice can make you falsely confident, and lead to worse memory.

7.4.2 Implications of findings

The first major implication from this study concerns the difficulty of translating well-established effects from experimental studies into more applied contexts: I chose two manipulations consistently shown to have strong effects on memory, but found that neither improved learning relative to training-as-usual and, indeed, one led to worse outcomes. The opportunity for real-world learners to self-regulate can lead to surprising outcomes where initial performance and experience is not predictive of eventual learning, as has been explored in detail in studies of metamemory (Bjork et al., 2013). Second, and relatedly, for clinicians my findings show that experience at the time of study or training, which may in many medical settings be the only practical measure of effectiveness, must be interpreted with caution: my data suggests that parents of children with complex medical needs would be more confident at the time of reading our schema-enhanced training material, but would likely benefit from it less. Finally, on a more positive note, my findings suggest that retrieval practice is potentially useful and unlikely to hurt learning, and may be of particular benefit when overconfidence is a problem. Specifically, my findings support the importance of retrieval for countering false confidence and improving self-regulated learning, while providing limited evidence for directly improving memory for the information.

7.4.3 The potential benefits of retrieval interventions

The testing effect is a robust finding in experimental studies (Rowland, 2014). Unexpectedly, in the control condition the retrieval practice intervention did not improve performance, although there was a main effect of retrieval on confidence ratings in the test. I designed the intervention to reflect how retrieval practice could be incorporated into the real world context of training parents to provide complex medical care. The study material was a complex text and the retrieval practice intervention involved open-ended free recall prompted by general topic headings, rather than directed cued-recall of simpler information such as vocabulary learning word-pairs. Although a testing effect has been found for prose in some studies (Kang, McDermott, & Roediger, 2007; Roediger & Karpicke, 2006a), there is less evidence for the testing effect with this type of material (Rowland, 2014). Recent studies have begun to explore potential boundary conditions of the testing effect that are relevant to our study, including concerns that the effect decreases or disappears for complex information that is high on element interactivity (i.e., study information that is related such as instructional text) (van Gog & Sweller, 2015), or when retrieval practice and the critical memory test have topically related questions, rather than identical questions (Wooldridge et al., 2014). Understanding these boundary conditions will be a critical step in understanding whether and how to harness the benefits of retrieval practice in applications such as enhancing medical training. Some of these boundary conditions may help to explain why I did not find a benefit of retrieval practice in the control version of the booklet; however it is also possible that by using a different format of retrieval intervention we may see benefits.

It is possible that we might find improvements in memory by using a different format of retrieval intervention. It has been suggested that more demanding retrieval practice

interventions may have greater benefits for final retention of the information (Kang et al., 2007). According to a meta-analysis on the testing effect, effect sizes are larger with cued recall tests as the recall activity, rather than a free recall or recognition task (Rowland, 2014). Feedback alongside retrieval practice has been shown to give the largest effects (Butler and Roediger, 2008, Cull, 2000, Roediger and Pyc, 2012). In the next chapter I will explore a different format of retrieval intervention (in the form of a cued recall test), with feedback on participants' answers. I hypothesise that this enhanced retrieval intervention may lead to improved memory when compared to a control condition of studying the information.

7.4.4 Strengths and limitations

As a proof-of-concept study for a possible intervention, my study necessarily has limitations in relation to both previous carefully-controlled experimental studies and the intended practical setting. First, I made choices to design this study in a way that was relevant to the applied setting of interest—i.e., training parents to care for children with feeding tubes—and therefore did not control participants' study time, unlike in many of the experiments in the literature. The time participants spent studying in Sessions 1 and 2 was variable between the conditions. Participants spent less time re-studying the information in the schema condition. Controlling for time would seem artificial when trying to apply these effects in the context of the real-world problem of training families. Participants self-regulate their learning which affects motivation to restudy and duration of study time (Bjork et al., 2013; Dunlosky & Rawson, 2012). Rawson, O'Neill & Dunlosky (2011) found that incorporating support for self-regulated learning can improve memory for information in patient education materials (Rawson et al., 2011). Second, the participants in this study were not parents of children with complex needs. Differences in

motivation levels and experience may affect the generalisability of our results. However to mitigate against this, our participants were of parent age and they were incentivised by payment for the study. Participants who failed the compliance checks of a minimum reading time were screened out in Session 1 to remove unmotivated participants. As such, this type of experiment offers a relatively practical way of exploring different interventions for training. Running the experiments with parents of children with emerging complex needs would be logistically challenging, given that only around 80 children in a hospital have gastrostomy surgery each year. Online experiments offer a way of exploring possible interventions in a controlled environment, before deciding what type of intervention might be worth testing in the applied setting.

7.5 Conclusions

In summary, in this experiment we found that schema- and retrieval-enhancements did not improve memory for complex medical information. The schema-enhancements in this experiment were in fact harmful to learning, but performance was rescued by retrieval practice. From an applied perspective, I would caution against schema-enhanced learning materials, as they may lead to false confidence and less time or motivation to continue studying information, which when study time is not controlled, is potentially dangerous. Retrieval practice seemed to have an important metacognitive function and may protect against over-confidence, but had no clear direct effect on learning, although this approach deserves further exploration given its success in educational settings (Rawson et al., 2011; Schwieren et al., 2017). Different formats of retrieval practice have been utilised in the literature, with larger effect sizes when feedback is included (Rowland, 2014). The next experiment will explore a different format of retrieval

intervention to see if an enhanced retrieval intervention with feedback included can improve memory.

Chapter 8 Retrieval-enhanced training for learning medical information

8.1 Introduction

The previous experiment found a detrimental effect of schema-enhanced training compared to restudy, which was rescued by the retrieval intervention. The retrieval intervention did not, on its own, lead to better memory for the information, however retrieval did seem to help with countering false confidence and improving self-regulated learning with schema-enhanced material. It is possible that a different format of retrieval intervention may lead to better memory. Different formats of retrieval intervention have different effect sizes (Rowland, 2014). For instance, retrieval interventions that are more demanding are thought to have larger effects on memory (Kang et al., 2007). Larger effect sizes have also been reported when feedback is included as part of the retrieval intervention (Rowland, 2014). This next experiment follows on from the previous experiment, to explore a different format of retrieval intervention to see if an enhanced retrieval intervention with feedback included can improve memory.

8.1.1 This study

The experiment evaluated whether an enhanced retrieval-based training intervention would improve memory for information about a complex medical task (gastrostomy care), using a between-participants design. Participants in the baseline group were asked to read an existing information booklet on gastrostomy care from the NHS. A second group received the retrieval-enhanced training which included one to three short-answer questions after each of the seven sections of the booklet, with feedback on their answer and additional schema-rich explanations on why it is the correct answer. A third group received the baseline information booklet with key facts repeated. All three groups

completed the same recognition memory test a week later. In the previous experiment I explored several different outcome measures for evaluating learning, with a cued-recall test as the primary outcome measure. This was difficult to score reliably but was sufficiently sensitive to detect differences between conditions. In this experiment I opted to use a recognition memory test with 20 multiple choice questions, as this is common in studies on the testing effect and is easy to score reliably. I predicted that the enhanced retrieval-based training would improve learning compared to both control conditions, reflected in increased memory performance in the final test session.

8.1.2 Aims of this study

This study compares training-as-usual for gastrostomy care (an NHS information booklet) with retrieval-enhanced training, and a further control condition where participants read the information with key facts repeated. I predicted that performance on a delayed recognition memory test would be significantly better in the retrieval-enhanced training condition than in control conditions that lack these manipulations (read information once, and read information and key facts). This hypothesis was tested in a design that compares learning (measured as delayed recognition memory accuracy) across the three conditions.

8.2 Methods

8.2.1 Participants

My pre-registered target sample size was at least 159 participants completing both sessions, with a minimum of 53 participants in each group (osf.io/6dbxt). This was calculated based on detecting a medium effect size, with a power of 0.8 and an alpha level of $p < 0.05$. Participants were from the United Kingdom and fluent in English. In total

211 participants were initially recruited via the online platform Prolific Academic, and 180 (85%) completed the full study (the training and test session). A flow chart in Appendix 10 shows the participant drop-out rate including the numbers of participants excluded for poor compliance. My final sample consisted of 180 participants. The mean age was 35 years (*SD* = 8.3). The sample was 63% female, 62% had degree level qualifications and 38% had school and college-level qualifications. All participants were from the United Kingdom and fluent in English. All participants self-certified that they did not work in healthcare, and had no previous experience caring for somebody with a feeding tube, and therefore did not have extensive prior knowledge of feeding tube care. Participants completed the study online, remotely and were paid for their time via Prolific. All participants gave informed consent before taking part. I received ethical approval for the study from The Medical Sciences Inter-Divisional Research Ethics Committee at the University of Oxford (Reference: R61895/RE001). Approval for this study was granted on the basis of revisions to the ethics application for the study in Chapter 7.

8.2.2 Design

The experiment consisted of two sessions. On day 1 participants completed the learning session and on day 6-8 they completed the test session which was a multiple choice recognition memory test. Participants were randomised at the start of Session 1 into three conditions for the learning session (using the randomisation function in Qualtrics which ensures an even number of participants in each group): the three conditions were read information once (information taken from an NHS booklet), read information with key facts, and enhanced training (retrieval-enhanced training with feedback). All participants completed the same test on day 6-8. There were 64 participants in the control group, 63 in the control and retrieval group and 53 in the retrieval-enhanced

training. Uneven numbers in each group were a result of unequal drop-out rates during Session 1: more participants in the retrieval-enhanced group did not complete the full session (this is probably because it took longer to complete, and participants were given the same rate of pay regardless of which learning session they were randomised to). Only participants who fully completed Session 1 were invited to complete Session 2 and included in the analysis.

8.2.3 Materials

Session 1 consisted of information from an existing NHS booklet on gastrostomy care (care of a PEG)[2]. The enhanced training included one to three short-answer questions after each of the seven sections of the booklet, with feedback on participants' answers and additional schema-rich explanations on why it is the correct answer. An example of a short answer question is "In the first few days, how should you clean the stoma site?" with an open-ended box for responses which required participants to enter a response before moving to the next page. Figure 8.1 shows an example of the feedback given to this question and the additional schema-rich explanation provided. Participants were presented with the correct answer and the answers they had given to compare. Figure 8.2 shows an example of the key facts presented in the control with key facts condition. The content of the key facts was the same as the answers to the short-answer questions in the retrieval-enhanced training condition. Participants in this condition were not asked to recall anything or presented with schema-rich explanations.

[2] https://www.patientsafetyoxford.org/clinical-safety-programmes/previous-programmes/paediatric-gastrostomy/overview/paediatric-gastrostomy-resources/booklets-for-parents/

YOU SAID: with gauze and cool boiled water

ANSWER: Clean the stoma site with cool boiled water and gauze.

Why? The area where the PEG tube enters the stomach is called the stoma site. Think of the stoma site like a wound. It takes a little while for any wound to heal. It is important to ensure the stoma site doesn't get infected and there aren't any complications like any leaking from the stomach, or redness, swelling, irritation or skin breakdown. Cleaning the wound with cool boiled water and gauze helps prevent infection while it heals. Boiling the water first and then cooling it ensures the water is sterile.

Figure 8.1 Example of feedback from short answer questions and additional schema-rich explanation on why this is the correct answer

DAILY CARE

Key fact: It is really important that you **wash your hands** before and after touching the gastrostomy site or doing a procedure.

Key fact: You need to clean the stoma site with cool boiled water and gauze in the first few days.

Key fact: The tube should be turned daily.

Figure 8.2 Example of key facts given after each section in the control information with key facts condition

8.2.4 Procedure

8.2.4.1 Session 1

Participants were instructed to switch off their phone/email/music before they started the study. They were informed that the study consisted of two sessions and that they would be given a small monetary bonus based on performance in the test in the second session to incentive participants to study the information carefully. Firstly, they completed demographic questions (age, gender and education). Next participants were randomised to receive either the enhanced training, control information or control with key facts.

In the retrieval-enhanced training, participants completed retrieval activities after each of the seven sections in the booklet, e.g. “In the first few days, how should you clean the

stoma site?" with an open-ended box for responses. The retrieval task was designed to be open-ended since the testing effect has been found to be stronger when the retrieval activity is cued-recall based rather than a recognition test such as multiple choice question (Rawson & Zamary, 2019). Each of these questions was followed by feedback on participants' answers and additional schema-rich explanations as described above. In the control condition with key facts, participants were asked to study key facts for each section of the booklet after written the basic text. The key facts were the same as the answers to the questions in the retrieval-enhanced training.

Minimum reading times were set, with a timer on each section of the study information. Participants were not able to proceed to the next page until the minimum time had elapsed (set at a fast reading speed of 700 words per minute). I also included two attention checks (e.g. "It is important you pay attention to this study. Type in the word "stomach" without any spaces"). If participants failed one or both of the attention checks (left it blank or misspelt the word), they were not invited to complete the test session.

At the end of the session, participants rated three questions on 7-point Likert scales: i) how easy the information was to understand (from "very hard to understand" to "very easy to understand), ii) the amount of information given (from "far too little information" to "far too much information") and iii) how confident they were that they would remember the information in a weeks' time (from "not at all confident" to "very confident").

Unlike in the previous experiment, I did not include a covariate in this study to account for individual differences in memory performance, attention and compliance. In the previous experiment, the covariate was used to increase the power of the design to

detect an effect. The interaction effect between the schema-enhanced materials and the retrieval-enhancement was significant, even without the covariate included in the model. We reasoned that since we would need to detect a medium to large effect in this experiment for this to translate into clinically meaningful improvements in outcome, including the covariate in this experiment was not sufficiently worthwhile, especially given the time it took participants to complete. I did however include attention checks and minimum reading times to exclude participants with poor compliance or attention.

8.2.4.2 Session 2

Participants were asked 20 four-option multiple choice questions testing their memory and understanding of the information they had studied in Session 1. The questions were forced-choice. Participants were asked the select the 'best answer'. For each question they were asked to rate their confidence in their answers on a 7 point scale with 1 indicating 'guessing', 4 'moderately confident and 7 'certain'.

8.3 Results

8.3.1 Performance in the recognition memory test

My key pre-registered analysis focused on Session 2 memory performance in the 20-item recognition memory test for booklet material. The proportion of questions answered correctly in the memory test ranged from 20% (5 out of 20) to 95% (19 out of 20). The mean overall score was 64% (*SD* = 17%). The mean proportion correct was numerically highest for participants in the group receiving the retrieval-enhanced training (*M* = 66%, *SD* = 18%), followed closely by the control with key facts condition (*M* = 65%, *SD* = 16%). Performance was lowest for participants in the control condition (*M* = 60%, *SD* = 17%) (Figure 8.3). To evaluate the recognition memory test scores, I ran a one way analysis of

variance (ANOVA), with type of training as the independent variable and proportion correct on the recognition memory test as the dependent variable. The analysis revealed no significant main effect of type of training: $F(2,177) = 2.23$, $p = .11$.

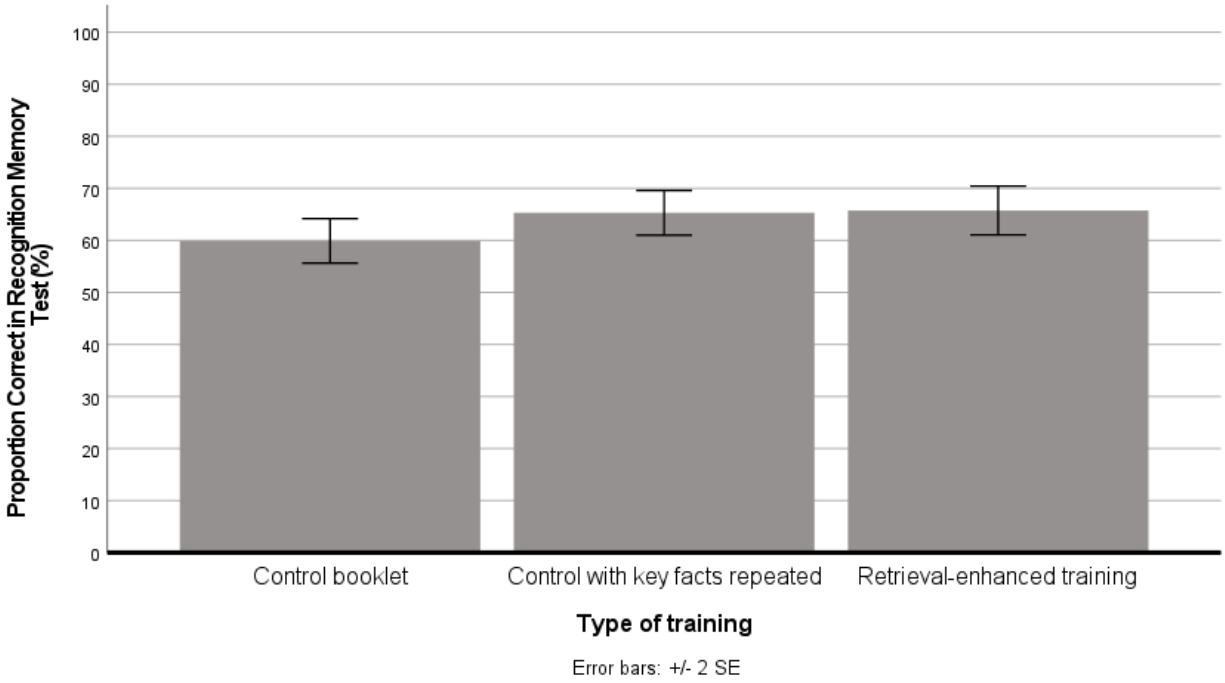


Figure 8.3 Proportion correct in the recognition memory test for the three types of training

Although it is possible with more power to detect an effect we might find a small benefit of the retrieval-enhanced training or the addition of key facts compared to the control condition, this is unlikely to clinically meaningful in the real-world context of training parents to care for children with gastrostomies.

8.3.2 Confidence ratings in the recognition memory test

These patterns of objective memory performance were largely reflected in our secondary outcome measure of participants' subjectively rated confidence in their recognition memory test (Figure 8.4). For each of the 20 questions in the recognition memory test, participants rated their confidence on a scale from 1-7 in steps of 1, with 1 labelled as

'guessing, 4 as 'moderately confident' and 7 as 'certain'. Mean confidence ratings ranged from 1.90 to 6.95 (*M* = 4.52, *SD* = 0.94). Confidence ratings were highest for participants in the retrieval-enhanced training condition (*M* = 4.66, *SD* = 0.98), closely followed by the control with key facts (*M* = 4.59, *SD* = 0.94). Mean confidence was lowest in the control group (*M* = 4.34, *SD* = 0.90).

To evaluate the confidence ratings, I ran a one way analysis of variance (ANOVA), with type of training as the independent variable and proportion correct on the recognition memory test as the dependent variable. The analysis revealed no significant difference in mean confidence between conditions: $F(2,177) = 2.01$, $p = .14$.

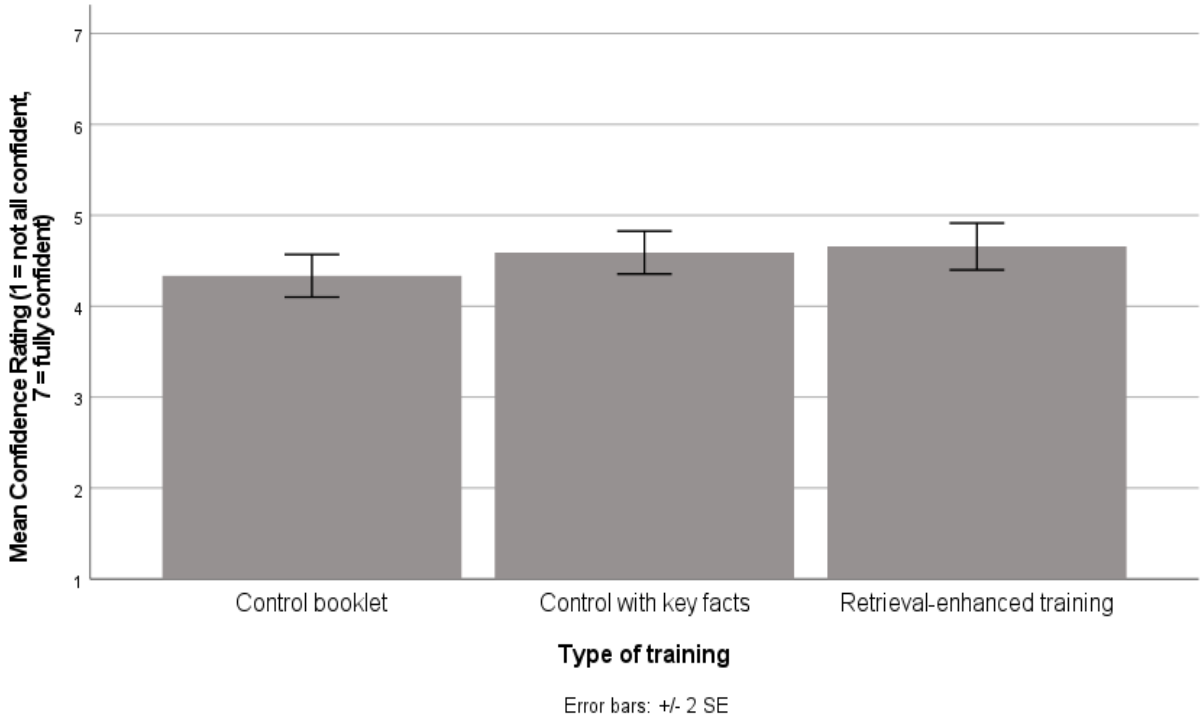


Figure 8.4 Mean confidence ratings for the three types of training

8.3.3 Mean confidence for correct answers only on the recognition memory test

My additional pre-registered secondary outcome measure was mean confidence for correct answers only. This is a potentially more sensitive measure than mean confidence for all answers. It was intended to capture whether when participant were correct, whether they were more confident that they were correct. Mean confidence scores for correct answers only (removing any wrong answers from the calculation) followed the same pattern as mean confidence for all answers: confidence was highest in the retrieval-enhanced training (M = 4.84, SD = 0.95), followed by the control and key facts group (M = 4.81, SD = 0.94) and lowest in the control condition (M = 4.63, SD = 0.95). In order to evaluate the mean confidence ratings for correct answers only, I ran a one way analysis of variance (ANOVA), with type of training as the independent variable and mean confidence for correct answers as the dependent variable. There was no significant main effect of type of training (F<1).

I also conducted some further exploratory analyses examining different types of outcome measures, including the calibration between confidence and scores on the memory test and analyses of the number of dangerous answers participants selected (see Appendix 11). I did not find a statistically reliable difference between the three conditions for any of the additional exploratory outcome measures.

In summary, analysis of the main outcome measures followed the predicted pattern, however the differences were not statistically significant for any of the three pre-registered outcome measures. Numerically, the highest memory scores and confidence ratings were in the retrieval-enhanced condition followed closely by the control condition with key facts. The lowest memory and confidence scores were in the control condition. I

designed this study with sufficient power to detect medium-effect sizes: small effect sizes are unlikely to be meaningful in the real-world context of training families. Whilst there may be a small benefit of the retrieval-enhanced training, the findings suggest it is not likely to make a big difference in the real world.

8.3.4 Study time in Session 1

This section briefly describes differences in study time between the conditions. The mean study time was 10.5 minutes in the control condition (*SD* = 4.5) and 12.8 minutes for the control with key facts (*SD* = 5.8). The retrieval-enhanced training took participants twice as long: the median study time was 21.9 minutes (*SD* = 6.1). Considering the retrieval-enhanced training was considerably longer than the other conditions, it did not lead to substantially better retention of the information.

8.3.5 Participants' ratings of the learning materials

This next section examines participants' ratings of the learning materials in the first session. At the end of session 1 (the training session), participants were asked some summary questions about the content of the training they received. They were asked to rate three statements on Likert scales from 1 to 7 for i) amount of information, ii) ease of understanding of the materials, and iii) judgement of learning reflecting how confident they were that they would remember the information in a weeks' time.

8.3.5.1 Ratings of amount of information

Participants rated amount of information on a scale from 1 to 7: 1 = far too little information, 4 = right amount, 7 = far too much information. The mean rating were similar across all three conditions: the control condition (*M* = 4.7, *SD* = 0.9), control with key facts (*M* = 4.6, *SD* = 0.9) and the retrieval-enhanced training (*M* = 4.7, *SD* = 1.0). There

was no significant main effect of type of training on participants ratings of the amount of information they were given *(F*<1). Although the retrieval-enhanced training took longer to complete, participants did not feel they were presented with too much information.

8.3.5.2 Ease of understanding of the training materials

Participants rated how easy the information was to understand, where 1 = very hard to understand, 4 = moderately easy and 7 = very easy to understand. Participants rated the control and key facts information as easiest to understand (*M* = 4.9, *SD* = 1.4), followed by the control condition (*M* = 4.7, *SD* = 1.4). The retrieval-enhanced training was rated as least easy to understand (*M* = 4.2, *SD* = 1.4). In order to evaluate the participants' ratings for ease of understanding, I ran a one way analysis of variance (ANOVA), with type of training as the independent variable and ease of understanding as the dependent variable. There was a significant main effect of type of training on how easy participants found the information to understand: $F(2,177) = 3.67$, $p = .03$, $\eta^2 = .04$. Post-hoc comparisons using a t Test with bonferroni corrections indicated that the retrieval enhanced training (*M* = 4.2, *SD* = 1.4) was rated as significantly less easy to understand that the control condition with key facts (*M* = 4.9, *SD* = 1.4). However the control condition did not significantly differ from control with key facts or retrieval-enhanced training.

8.3.5.3 Judgements of learning

Participants gave judgements of learning at the end of Session 1, rating their confidence that they would remember the information in the final test, on a scale from 1 ("not at all confident") to 7 ("very confident"). Judgements of learning were numerically highest for participants given the control and key facts training (*M* = 3.5, *SD* = 1.4), followed by the

control version (*M* = 3.2, *SD* = 1.1). Consistent with the previous experiment where retrieval practice reduced self-report confidence at the time of study, judgements of learning were lowest in the retrieval-enhanced training (*M* = 2.8, *SD* = 1.1)

In order to evaluate the participants' judgements of learning, I ran a one way analysis of variance (ANOVA), with type of training as the independent variable and participants' judgements of learning as the dependent variable. There was a significant main effect of type of training on how confident participants were to remember the information in a weeks' time: $F(2,177) = 5.28$, $p = .006$, $\eta^2 = 0.06$. Follow-up pairwise comparisons (using a t-test with bonferroni corrections) indicated that judgements of learning were significantly lower for the retrieval-enhanced training (*M* = 2.8, *SD* = 1.1) than for the control condition with key facts (*M* = 3.5, *SD* = 1.4). The pairwise comparison for the control condition with control with key facts was not significant, nor was the pairwise comparison for the control condition with retrieval-enhanced training.

In summary, participants' ratings of the information at the time of study followed a different pattern to the final memory performance scores and associated confidence ratings. Participants did not rate the retrieval-enhanced training as too long, however they did rate is as less comprehensible than the control condition or control with key facts. Consistent with the previous experiment, the retrieval intervention reduced participants' judgements of learning. Rating of confidence at the time of study were lowest in the group who received the retrieval-enhanced training, although numerically performance in the final test a week later was highest for the retrieval-enhanced training. Ratings of understanding and judgements of learning do not always translate into better performance in a subsequent memory test.

8.4 Discussion

8.4.1 Summary

This experiment evaluated whether retrieval-enhanced training with feedback would improve naïve participants' retention of information about a complex medical task (gastrostomy care). Although performance in the recognition memory test and associated confidence ratings were highest in the group that received the retrieval-enhanced training, the difference was not statistically reliable. Numerically, adding key facts to the booklet was almost as beneficial as the retrieval-enhanced training. The study was powered to detect a medium effect size of 0.5, which was anticipated based on a meta-analysis of the testing effect with feedback (Rowland, 2014). It is possible there are marginal gains of the retrieval intervention, however the gains would likely be too small to bring about meaningful benefits for families. There was no evidence that the retrieval-enhanced training had a negative impact on learning (unlike the schema-enhanced training in the previous experiment), so practically there seems to be no harm in including retrieval interventions as part of training, but also however limited benefit. Self-ratings at the time of study of "feelings of understanding" do not always lead to improved performance in a memory test. More broadly this experiment, and the previous experiment in Chapter 7 suggest that there may only be marginal gains in adding to written materials. It is likely that we need multiple components in a training intervention to translate into something useful for families.

8.4.2 Outcome measures

One of the key questions in this experiment and the previous one is, which is the optimal outcome measure to use to evaluate learning? We need a measure that is sensitive, can

be scored reliably and at least partially reflects the real-world outcomes of interest. This experiment used multiple choice questions testing recognition memory, whereas the previous experiment used cued-recall questions. According to the literature there are slightly larger effect sizes for the testing effect in cued-recall tests in comparison to recognition memory tests (Rowland, 2014). However the recognition memory multiple choice questions are simpler to complete, and can be scored more reliably. It is also easier to record the confidence ratings for the recognition memory test within the design constraints of the experiment, compared to the cued-recall test. In this study I also explored a number of other possible outcome measures (e.g. to capture the calibration between accuracy and confidence), however I did not find a statistically reliable different between the training interventions for any of these outcome measures.

There are also other options for outcomes measures which are closer to what is measured in the real world for families which are beyond the constraints of online studies, such as observations of practice (e.g. videos of participants performing tasks on a mannequin which are coded by trained observers who have achieved a good level of inter-rater reliability). In practice, clinicians typically assess parents' competence by asking them to demonstrate tasks, sometimes against a list of competencies a parent needs to demonstrate, or simply ask parents whether they feel confident doing the tasks. In terms of evaluating real-world training intervention, there are also important clinical outcomes such as healthcare usage (e.g. calls to Community Children's Nurses, visits to A&E) and frequency of complications (e.g. gastrostomy site infections and broken equipment). Given we did not detect an effect of the retrieval intervention in the outcome measures in these two experiments (cued-recall and recognition memory tests and associated confidence ratings) which have been widely used in the experimental

literature, with medium effect sizes reported, we are unlikely to detect effects in more real-world outcomes such as observations of practice or healthcare usage. We would likely need a multi-component training intervention (e.g. with guided simulation practice on a mannequin, videos, interactive troubleshooting sessions with families and clinicians) to detect a difference in these real-world measures.

8.5 Conclusions

In summary, in this experiment I did not find a convincing benefit of the retrieval-enhanced training for improving memory for complex medical information. Although this training was more interactive and took longer to complete, numerically the group who studied the control booklet with key facts performed almost as well in the memory test as the group who received the retrieval-enhanced training. Retrieval-based interventions do not seem to be harmful (unlike the schema-enhanced training in the previous experiment), however they are unlikely to bring about clinically-meaningful differences (effects are likely to be small). Another implication from the two experiments is that participants' ratings of the information at the time (their judgements of learning and ratings of how understandable the information is) do not always translate into measures of objective memory performance: participants may rate the information as less understandable but perform well in a test. If we want to bring about clinically-meaningful differences in training for parents caring for medically complex children, we will likely need broader interventions. There may be limited benefits of adding to written information booklets.

In the next two chapters I develop and test training videos developed with parents and healthcare professionals. The use of videos is supported by the stakeholder supporting

my research and theoretically underpinned by dual-coding theory. The next chapter evaluates the training videos through an online experiment assessing whether they benefit learning.

Chapter 9 Video-enhanced training for learning medical information

9.1 Introduction

The ultimate aim of my thesis is to develop a package of training and support that can improve learning in the real-world context of training parents who care for children with gastrostomies. Various forms of evidence suggest that videos might be a helpful addition to training, and may lead to larger benefits than retrieval or schema-based interventions which did not lead to the benefits I predicted they might. This chapter explores whether videos can improve memory for medical information on caring for a gastrostomy. There are a number of reasons to think videos might help learning which I discuss below. However, as I found in the schema and retrieval experiment in Chapter 7, there is a danger that interventions that make information more understandable (which videos might), can lead to false overconfidence, as was the case for the schema-enhanced training. It is therefore important that we test whether videos, a seemingly intuitive intervention, leads to improved performance in similar experimental conditions as the previous two experiments.

The use of instructional videos as part of training is strongly supported by parents and clinicians. There is evidence in the literature of instructional videos being promoted for educating family carers to do medical procedures (Kirkland-Kyhn, Generao, Teleten, & Young, 2018). In the United States, the AARP Public Policy Institute have developed an extensive programme of instructional videos for common tasks carried out by family carers caring for older adults (https://www.aarp.org/ppi/initiatives/home-alone-alliance/family-caregiving-videos/). In the survey in Chapter 6 of my thesis, parents rated videos as more useful than written booklets, and most other forms of training.

Participants in the experiments in Chapter 7 also commented that the training would benefit from more images and videos. The stakeholder group of parents and healthcare professionals who are supporting my research felt strongly that videos would be beneficial for supporting parents' learning.

There are also strong theoretical reasons to think videos might help learning. According to dual-coding theory, written text that is presented alongside complementary images is better remembered than when text is presented on its own (Paivio, 1990). Multiple representations of the same information enhances memory for the information provided the accompanying visual representations are informative and carefully constructed (Mayer et al., 1990). The visual representations can be videos, animations, charts etc. (Mayer, 2002). Visual aids can serve multiple functions, including making the information more memorable, making the text easier to understand or providing a structural framework for the text (Carney & Levin, 2002). For example Bransford and Johnson found the addition of appropriate context pictures increased both participant's comprehension ratings and their recall of the information (Bransford & Johnson, 1972).

9.1.1 This study

Before we can test and implement any videos in the real-world setting, we must first check whether they aid learning. As we saw in the previous experiments, interventions that increase learners' ratings of understanding or their judgements of learning do not always lead to better memory for the information. This experiment thus evaluated whether video-enhanced training would improve memory for information about a complex medical task (gastrostomy care), using a between-participants design. Participants were randomised to receive one of three types of training. Participants in the

control group were asked to read an existing information booklet on gastrostomy care from the NHS. Participants in a further control condition studied the information alongside additional images and key facts. In the video-enhanced condition, the information booklet had accompanying videos co-produced with parents and healthcare professionals which supplement each section of the written information. The educational videos were developed alongside the clinical team at the John Radcliffe hospital, nurses from community services and parent representatives. The development of the videos was informed by findings from the parent survey in Chapter 6, e.g. that the majority of parents wanted both families and healthcare professionals to feature in videos and wanted at least some videos to be filmed at home. All three groups were tested on their memory for the information 6-8 days later, with accompanying confidence ratings, and a final task asking participants to put instructions in the correct order. I predicted that the video-enhanced training would improve learning, reflected in increased memory performance and confidence in the test session.

9.1.2 Aim of the study

The aim of this experiment was to determine whether video-enhanced training improves memory for information about a complex medical task (gastrostomy care).

9.2 Methods

9.2.1 Participants

My pre-registered target sample size was at least 159 participants completing both sessions, with a minimum of 53 participants in each group (osf.io/qrxe9). This was calculated based on detecting a medium effect size, with a power of 0.8 and an alpha level of $p < 0.05$. In total 205 participants were initially recruited via the online platform

Prolific Academic, and 167 (81%) completed the full study (the training and test session). A flow diagram in Appendix 10 shows the participant drop-out rate including the numbers of participants excluded for poor compliance. My final sample consisted of 167 participants. Participants were from the United Kingdom, fluent in English and aged between 18 and 50. The same inclusion and exclusion criteria were applied as in the previous chapter. Participants who had taken part in either of the previous two experiments were excluded from participating in this study. Participants were paid for their time, with a small bonus payment awarded for good performance in the test to incentivise participants to study the information carefully.

The mean age was 35 years (*SD* = 8.2). The sample was 62% female, 71% had degree level qualifications and 29% had school and college-level qualifications. All participants were from the United Kingdom and fluent in English. All participants self-certified that they did not work in healthcare, and had no previous experience caring for somebody with a feeding tube, and therefore did not have extensive prior knowledge of feeding tube care. Participants completed the study online, remotely and were paid for their time via Prolific. All participants gave informed consent before taking part. Ethical approval for the study was received by The Medical Sciences Inter-Divisional Research Ethics Committee at the University of Oxford (Reference: R61895/RE001). I received approval for revisions to my ethics application from the study in Chapter 7.

9.2.2 Design

The experiment consisted of two sessions. On day 1 participants completed the first learning session and on day 6-8 they completed the test session. The experiment had a between subject design with three groups: i) read information once (*N* = 59), ii) read once

with additional still images and key facts (*N* = 55), and iii) video-enhanced training (*N* = 53). Participants were randomised to receive one of the three types of study materials at the start of Session 1 using the randomisation function in Qualtrics (using the same process as used in the experiment in Chapter 8). All participants received the same test in Session 2.

9.2.3 Materials

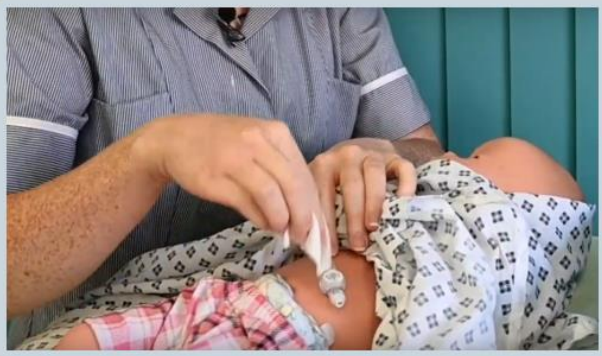
Session 1 consisted of information from an existing NHS booklet on gastrostomy care (care of a gastrostomy button)[3]. The previous experiments used an NHS booklet for a different type of gastrostomy device (a PEG tube): routine practice at the JR changed in 2019-2020 to insert a gastrostomy button as a primary procedure rather than inserting a PEG tube first. The material from the booklet was restricted to routine care only, to keep the experiment a reasonable length. Each section of the booklet had an accompanying video (what is a gastrostomy button, infection control, daily care of the gastrostomy button, weekly care using a gastrostomy button, administering a feed and administering medication via a button extension). Appendix 13 provides the video links used. Some of videos were coproduced my myself, parents and healthcare professional and some were existing videos created by healthcare organisations in the UK. For the control condition with additional images and key facts, each section of the booklet was followed by key facts (between two and six), which were statements taken from the audio transcript of the relevant video, and screenshots (between two and six) from the video. Figure 9.1 shows an example section.

[3] https://www.patientsafetyoxford.org/clinical-safety-programmes/previous-programmes/paediatric-gastrostomy/overview/paediatric-gastrostomy-resources/booklets-for-parents/

Key facts

Remember to wash your hands before cleaning the stoma site.

In the first seven days of the button being inserted, this can be cleaned with gauze and cooled boiled water. This should be cleaned in a circular motion around the button and dried thoroughly.



Once dry the button should be rotated 360 degrees.

After the button has been inserted for a week, it can then be cleaned as part of your child's daily routine. This can be done in the bath or shower with a washable cloth such as a flannel.

If bathing, you will need to ensure the safety cap for the button is closed.

You should monitor the site for any changes in the skin. If there are any changes, you should see your community nurse, especially if there's new discharge or a big area of redness up to 1 or 2cm in the skin around the button.

*The images and key facts are taken from the video on daily care of the gastrostomy button, as used in the video-enhanced condition: https://youtu.be/Ql-PmNjewx4

Figure 9.1 Example of a section of the booklet for the control condition with additional images and key facts

9.2.4 Procedure

9.2.4.1 Session 1

Participants were instructed to switch off their phone/email/music before they started the study. They were informed that the study consisted of two sessions. Participants were randomised to receive one of the three versions of the gastrostomy information. They were instructed to read the information carefully and told explicitly that they would not be invited to take part in Session 2 if their data indicated that they had not followed the instructions to read the information carefully. Minimum reading times were set, with a timer on each section of the study information. Participants were not able to proceed to the next page until the minimum time has elapsed (set at a fast reading speed of 700 words per minute). For the video-enhanced condition, the time taken to watch the full video was included in the minimum time allowed to proceed to the next page. I also included the same two attention checks as in the previous experiment in Chapter 8. At the end of the session, participants rated the same three questions from the previous experiment on 7-point Likert scales: i) how easy the information was to understand, ii) the amount of information given and iii) how confident they were that they would remember the information in a week's time.

9.2.4.2 Session 2

Participants were asked 20 multiple choice questions testing their memory and understanding of the information they had studied in Session 1. The questions were forced choice, with four possible options. Example questions included "What is the purpose of priming the extension tube?" and "When does the button need to be turned (select the best answer)?". The questions and answers were designed in consultation with my clinical collaborators. For each question, participants were asked to rate their

confidence in their answers on a 7-point scale with 1 indicating 'guessing', 4 'moderately confident and 7 'certain'. Participant were then asked to complete three questions requiring them to put instructions in the correct order, e.g. for connecting the extension tube to the button (see Figure 9.2 for an example). For each of these questions, they rated their confidence level.

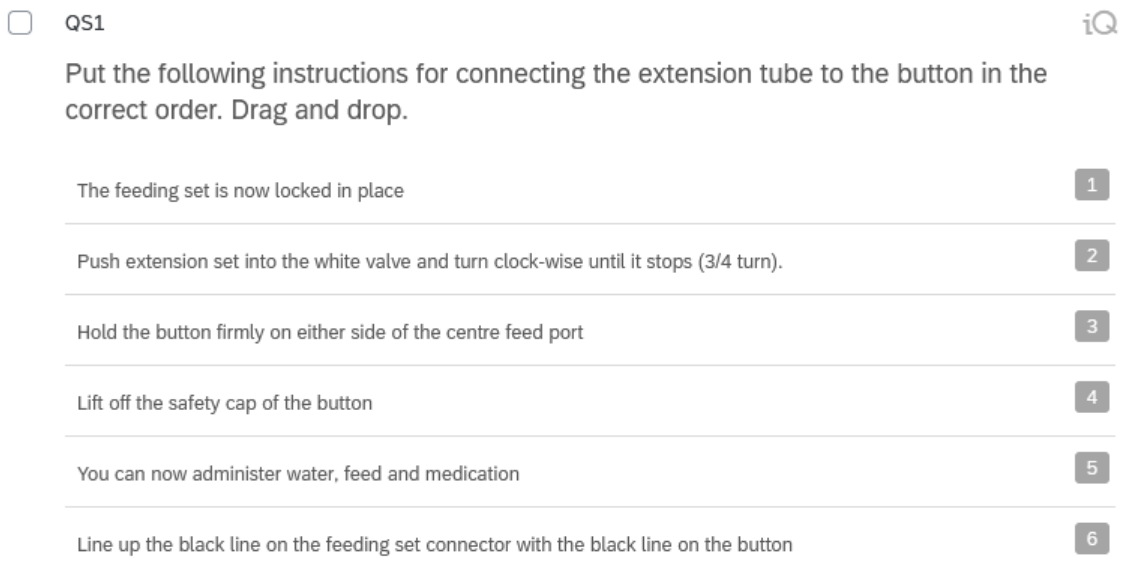


Figure 9.2 Example of an ordering instructions question. The correct answer is: 4, 6, 3, 2, 1, 5.

9.3 Results

9.3.1 Performance on recognition memory test

My key pre-registered analysis focused on Session 2 memory performance in the 20-item recognition memory test for booklet material. The proportion of questions answered correctly in the recognition memory test in Session 2 ranged from 20% to 100% across participants. The mean score across all conditions was 62% (*SD* = 18%). Performance was weakest in the control condition (*M* = 53.4%, SD = 15.8%), followed by images and key facts (*M* = 65.0%, *SD* = 15.9%), and strongest in the video-enhanced condition (*M* = 67.8%, *SD* = 17.8%), as illustrated in Figure 9.3.

In order to evaluate the scores on the memory test, I ran a one way analysis of variance (ANOVA), with type of training as the independent variable and proportion correct on the recognition memory test as the dependent variable. There was a significant effect of type of training on performance in the test: $F(2,164) = 12.4$, $p < .001$, $\eta^2 = 0.13$.

Follow-up pairwise comparisons (using t-tests with Bonferroni correction for multiple comparisons) indicated that performance in the test was significantly better for the video-enhanced condition than for the control booklet; $t(110) = 4.57$, $p < .001$. Performance was also significantly better for the control condition with additional images and key facts than for the control booklet; $t(112) = 3.92$, $p < .001$. However performance on the video-enhanced condition was not significantly different from the control condition with additional images and key facts; t(106) = .87, *n.s.*

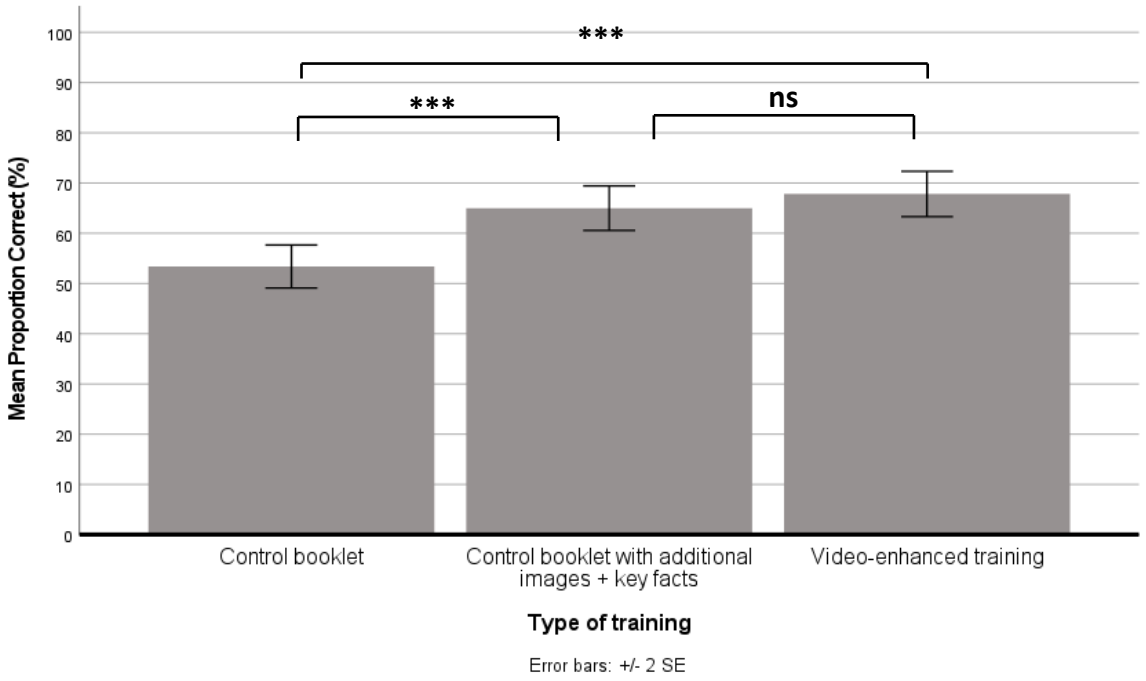


Figure 9.3 Proportion correct in the recognition memory test by type of training

9.3.2 Mean confidence on the recognition memory test

These patterns of objective memory performance were largely reflected in my secondary outcome measure of participants' subjectively-rated confidence in their recognition memory test answers (see Figure 9.4), calculated as the mean rating on the 1-7 scale across the 20 questions answered. Mean confidence ratings ranged from 1.50 to 6.55 with a mean of 4.32 (*SD* = 1.15). Mean confidence was highest in the video-enhanced condition (*M* = 4.70, *SD* = 0.98), closely followed by the control condition with additional images and key facts (*M* = 4.55, *SD* = 1.15) and lowest for the control booklet (*M* = 3.77, *SD* = 1.11). In order to evaluate the confidence ratings in the memory test, I ran a one way analysis of variance (ANOVA), with type of training as the independent variable and mean confidence on the recognition memory test as the dependent variable. There was a significant difference in mean confidence between conditions: $F(2,164) = 12.2$, $p < .001$, $\eta^2 = .13$.

Follow-up pairwise comparisons (using t-tests with Bonferroni correction) indicated that confidence was significantly higher for the video-enhanced condition than for the control booklet; $t(110) = 5.70$, $p < .001$. Confidence was also significantly higher in the control condition with additional images and key facts than for the control booklet; $t(112) = 3.71$, $p < .001$. However mean confidence for the video-enhanced training did not significantly differ from the control booklet with additional images and key facts; $t(106) = .71$, *n.s.*

Corresponding results were observed in a pre-registered secondary analysis which focused on confidence ratings for correctly-answered questions only. Confidence for correct answers was highest in the video-enhanced training (*M* = 4.89, *SD* = 1.07), closely

followed by the control condition with additional images and key facts (*M* = 4.79, *SD* = 1.19) and lowest for the control booklet (*M* = 4.06, *SD* = 1.25).

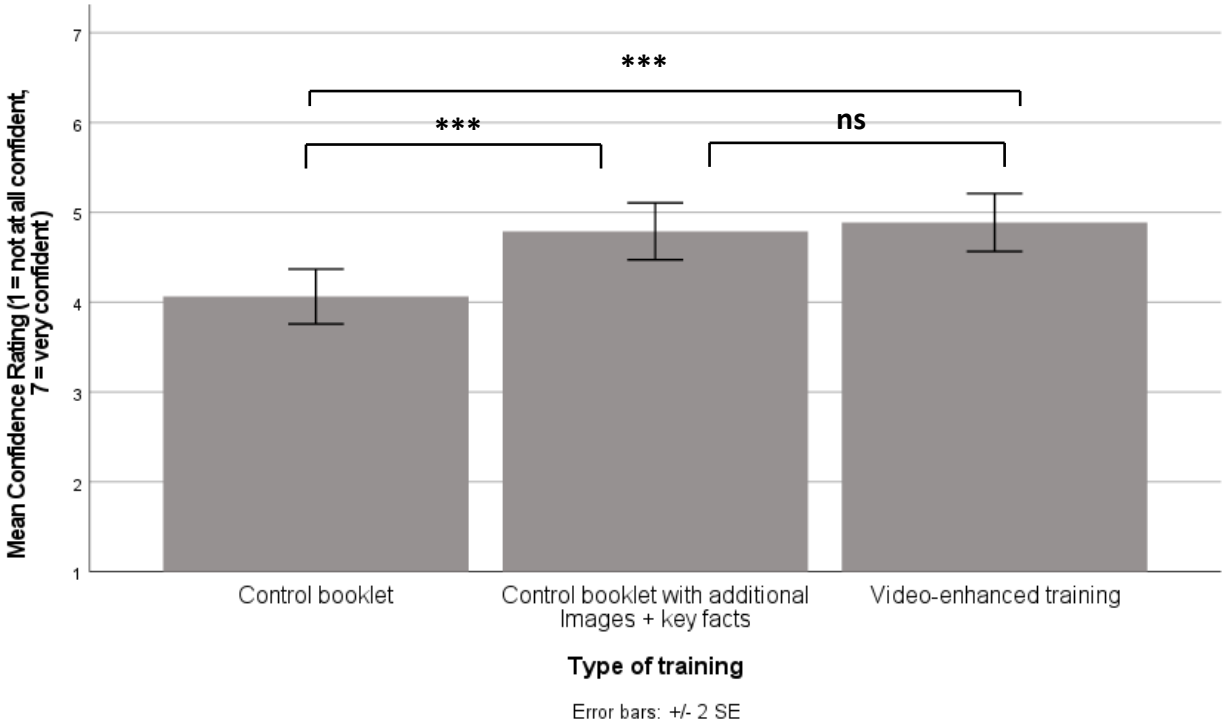


Figure 9.4 Mean confidence ratings in recognition memory test by type of training

9.3.3 Performance on the ordering instructions task

An additional outcome measure explored in this study was performance on an ordering instructions task. Throughout the last few chapters, I have explored a number of different outcome measure intended to capture something conceptually closer to the skills expected of parents caring for children with gastrostomies. In this experiment, I designed a test which required participants to put instructions in the correct order. I hypothesised that parent who watched the tasks in the videos would perform better at this task. Participants were asked three questions requiring them to put a series of instructions in the correct order (see Figure 9.2).

The ordering instructions questions were scored using Kendall's tau for each of the three questions, comparing the correct order (e.g. 6,4,1,3,5,2) with the participant's answer, i.e. the order in which they put the statements (e.g. 6,2,3,5,1,4). I then transformed the correlation coefficients (the Kendall's tau scores) to Z scores prior to calculating the mean of the three order instructions questions for each participant. The use of Fisher's Z transformation is recommended in this situation as correlations can only vary between –1 and +1 and averaging correlation coefficients can result in bias (Silver and Dunlap, 1987). After calculating the mean of the Z scores, I back-transformed the Z scores to correlations, resulting in a mean score for the ordering instructions questions for each participant. Mean Kendall's tau score was highest in the control condition with additional images and key facts (M = 0.68, SD = 0.15), followed by the video-enhanced condition (M = 0.66, SD = 0.17) and lowest in the control condition (M = 0.59, SD = 0.20). In order to evaluate performance on the ordering instructions questions, I ran a one way analysis of variance (ANOVA), with type of training as the independent variable and mean Kendall's Tau score as the dependent variable. There was a significant main effect of type of training: $F(2,164) = 3.98$, $p = .020$, $\eta^2 = .05$. Follow-up pairwise comparisons (using a t-test with Bonferroni corrections) indicated there was a significant difference between the control condition and the control with additional images and key facts; $t(112) = 2.58$, $p = .011$. There was also a significant difference between the video-enhanced condition and the control condition; $t(110) = 2.04$, $p = .044$. The video-enhanced condition did not significantly differ from the images with key facts condition; $t(106) = .47$, n.s. Similar to the primary outcome measures, both the video-enhanced training and the control condition with additional images and key facts led to improved performance on the ordering instructions test when compared to studying the control booklet. One of the

limitations of the ordering instructions task was that it only consisted of three questions: it would have been better to have had more questions, but unfortunately these questions were difficult to design and there was a limited number of possible questions based on the booklet material.

9.3.4 Confidence ratings on ordering instructions task

Participants gave associated confidence ratings for each of their answers in the ordering instructions task, as they did in the recognition memory test. Mean confidence ratings ranged from 1 to 7 with a mean of 3.72 (*SD* = 1.44). Mean confidence was highest in the video-enhanced condition (*M* = 4.05, *SD* = 1.49), followed by images and key facts (*M* = 3.92, *SD* = 1.29) and lowest in the control condition (*M* = 3.23, *SD* = 1.41). A one way analysis of variance (ANOVA), with type of training as the independent variable and mean confidence for the ordering instructions questions as the dependent variable, revealed a significant difference in mean confidence in the ordering instructions task between conditions: $F(2,164) = 11.0$, $p = .004$, $\eta^2 = .06$.

Follow-up pairwise comparisons (using t-tests with Bonferroni corrections) indicated that confidence for the ordering instructions task was significantly higher in the video-enhanced training than in the control booklet; $t(110) = 2.99$, $p = .007$. Confidence was also significantly higher in the control condition with images and key facts than in the control booklet; $t(112) = 2.69$, $p = .03$. However the video-enhanced condition did not significantly differ from the control booklet with additional images with key facts; $t(106) = .51$, n.s.

In summary, analysis of my outcome measures (performance on the recognition memory test, associated confidence rating and confidence ratings for correct answers only) all

confirmed the predicted pattern: numerically, memory scores and confidence ratings were highest in the video-enhanced training across nearly all outcome measures (except for the ordering instructions questions). This was closely followed by the control booklet with additional images and key facts. The lowest memory scores and confidence ratings were for the control booklet. Effect sizes were large for the video-enhanced training when compared to control booklet, however was no clear evidence of a benefit of the video-enhanced training over the control booklet with additional images and key facts.

9.3.5 Study time in Session 1

The mean study time was 12.4 minutes (*SD* = 8.4) for the control booklet and 15.7 minutes (*SD* = 6.7) for the control booklet with additional images and key facts. The video-enhanced training took participants around twice as long (*M* = 29.0, *SD* = 9.3). In order to investigate whether memory for the information was better in the video-enhanced training simply because study time was longer, I ran an analysis of covariance (ANCOVA) with type of training as the independent variable and proportion correct on the recognition memory test as the dependent variable and with study time included as a covariate. The effect of type of training on proportion correct on the recognition memory test remained significant; $F(2,163) = 9.41$, $p < .001$, $\eta^2 = 0.10$. The effect of the study time covariate was not significant; $F<1$. Further analysis on the relationship between study time and performance on the recognition memory test is presented in Appendix 14. These findings suggest it is not study time that is important for performance on the memory test, but what you do during the study time that matters.

9.3.6 Participants' ratings of the learning materials

As in the previous experiments, at the end of session 1, participants were asked some summary questions about the content of the training they received. They were asked to rate three statements on Likert scales from 1 to 7. In the previous experiments, ratings of how understandable the training materials are and judgements of learning at the time of study have not always followed the same pattern as performance in the outcome measures.

9.3.6.1 Ratings of amount of information

Participants rated amount of information on a scale from 1 to 7: 1 = far too little information, 4 = right amount, 7 = far too much information. The mean rating were similar across all three conditions: the control booklet (M = 4.5, SD= 1.1), control booklet with additional images and key facts (M = 4.5, SD = 1.0) and the video-enhanced training (M = 4.6, SD = 1.0). There was no significant main effect of type of training on participants ratings of the amount of information they were given ($F < 1$). Although the video-enhanced training took longer to complete, participants did not feel they were presented with too much information.

9.3.6.2 Ease of understanding of the training materials

Participants rated how easy the information was to understand, where 1 = very hard to understand, 4 = moderately easy and 7 = very easy to understand. Participants rated the video-enhanced training as easiest to understand (M = 5.0, SD = 1.1), followed by the control booklet with additional images and key facts (M = 4.2, SD = 1.4). The control booklet was rated as least easy to understand (M = 3.8, SD = 1.5). A one way analysis of

variance (ANOVA), with type of training as the independent variable and ease of understanding as the dependent variable, revealed a significant main effect of type of training on how easy participants found the information to understand: $F(2,164) = 11.8$, $p < .001$, $\eta^2 = 0.13$.

Post-hoc comparisons (using t-tests with Bonferroni correction) indicated that the video-enhanced training was rated as significantly easier to understand that the control booklet; $t(110) = 4.95$, $p < .001$. The video-enhanced training was also significantly easier to understand than the control booklet with additional key facts and images; $t(106) = 3.27$, $p = .007$. Ratings for how easy the information was to understand did not significantly differ between the control booklet and the control condition with additional key facts and images; $t(112) = 1.53$, $p = .31$.

9.3.6.3 Judgements of learning

Participants gave judgements of learning at the end of Session 1, rating their confidence that they would remember the information in the final test, on a scale from 1 ("not at all confident") to 7 ("very confident"). Judgements of learning were numerically highest for the video-enhanced training ($M = 3.9$, $SD = 1.2$), followed by the control booklet with additional image and key facts ($M = 3.4$, $SD = 1.2$). Judgements of learning were lowest for the control booklet ($M = 2.8$, $SD = 1.1$).

A one way analysis of variance (ANOVA), with type of training as the independent variable and participants' judgements of learning as the dependent variable, revealed a significant main effect of type of training on how confident participants were to remember the information in a week's time: $F(2,164) = 13.2$, $p < .001$, $\eta^2 = .14$. Follow-up pairwise comparisons (using t-tests with Bonferroni correction) indicated that

judgements of learning were significantly higher for the video-enhanced condition than for the control booklet; $t(110) = 5.27$, $p < .001$. However there was no significant difference between the video-enhanced condition and control booklet with additional images and key facts; $t(106) = 2.28$, $p = .056$. Judgements of learning for the control booklet with additional images and key facts were significantly higher than for the control booklet; $t(112) = 2.76$, $p = .02$.

In summary the video-enhanced training was rated as the most understandable and had the highest judgements of learning at the time of study. Although there was not a statistically reliable difference in memory performance in the second session between the video-enhanced training and the control condition with additional key facts and images, there was a statistically reliable difference in ratings of how understandable the materials were at the time of study. Participants in the video-enhanced condition did not feel like they were presented with too much information compared to the control conditions.

9.4 Discussion

This study demonstrates that adding either videos or images and key facts to a patient information booklet can significantly improve memory for the medical information, when compared to studying the written information alone. Results are broadly consistent with stakeholder input, and also align with theoretical work on dual coding theory (Carney & Levin, 2002; Mayer et al., 1990; Paivio, 1990). In contrast to the previous experiments, we found large effect sizes for the intervention (η^2 =0.13 for the primary outcome measure of proportion correct on the recognition memory test). The effect sizes found are large for psychological experiments, particularly for between-subject designs, which is an

encouraging finding for the real-world context (J. Cohen, 1988; Lakens, 2013). However, there was no clear benefit of videos for learning above adding images and key facts. Whilst the video condition was rated by participants as significantly more understandable and had higher judgements of learning than the control booklet with additional images and key facts, we did not find convincing evidence that the videos improved memory more than the enhanced booklet. It may be that there is a small benefit of videos over images and key facts for learning, but this would need to be tested with a much larger sample with power to detect smaller effects. Interestingly, in contrast to the retrieval training used in the experiments reported in Chapters 7 and 8, which reduced participants' confidence they would remember the information, the video-enhanced training led to higher ratings of confidence at the time of study, as well as the numerically-highest scores on the memory test in Session 2. In contrast to the previous experiments on retrieval practice and schema-enhanced training, there is a clearer message for clinical practice in terms of what enhances learning: images and videos can enhance learning, and are likely to be more helpful than enhancing training with schema and retrieval-based interventions.

9.4.1 Is it simply more study time that matters?

The video-enhanced training and the control booklet with additional images and key facts took participants longer to complete than the control condition of studying information from an NHS booklet. In practice, requiring parents to study for longer is not an important concern in this real-life context. However, notably in this experiment we found that adding study time as covariate, did not abolish the significant effect of type of training on performance on the recognition memory test. Consistent with other findings

in psychology, spending more time studying does not improve performance, it is what you do with the study time that matters: for example length of time in short term memory does not predict long term recall or recognition (Craik & Watkins, 1973), and restudying information alone does not improve performance on delayed recall test (Karpicke & Roediger, 2008). There will be large individual differences in how long parents spend studying information, just as there were large individual differences in study time for participants in this experiment within condition. Type of training is more important than studying for longer.

9.4.2 Do these findings apply to the real-world context?

There are of course important differences between the participants I recruited through Prolific and parents caring for children with complex medical needs, such as different levels of motivation. Some concerns relating to the external validity of these experimental findings have been discussed in Chapter 7. One important consideration is that in the real-life context parents may watch videos spaced out over time, for example, revisiting videos and written information after the surgery. It would be difficult to test this in an experiment with regular experimental participants, but it is possible that introducing more self-study and spacing out learning over time might affect the results. There are various potential boundary conditions that could be explored. In this experiment we purposely did not control participants' study time (allowing them to study the information as long as they wanted) which led to large individual differences in study time in this experiment. This in part reflects how we would expect people to study information in real-life contexts outside the lab, but it does not fully reflect the variability in study time and spaced-out study which would likely occur with parents learning to care

for a child's gastrostomy. It may be that if parents find the videos more engaging and understandable (this study reports evidence participants found the videos significantly more understandable than images and key facts or the control condition), that they may be more likely to re-watch videos than re-read written information which could influence learning, or conversely it could lead to false confidence with participants not revisiting the information as much.

9.4.3 Further research

Further research could investigate the boundary conditions of the effect found in this experiment. For example, it would be useful to test memory after a shorter or longer period, (e.g. test 1 day later or 1 month later) to establish whether clear effects of the added videos and images are observed. We could also investigate whether the findings are the same with participants who are experiencing high levels of stress, which parents of children with complex medical needs often experience (Cousino & Hazen, 2013), for example by recruiting participants who score above a certain cut-off point on a measure of stress, such as the widely-cited self-report measure 'Global Measure of Perceived Stress (S. Cohen, Kamarck, & Mermelstein, 1983). However in practice it is difficult to know which measure of stress best represent the stress parents of children awaiting gastrostomy surgery experience. The Stress Measurement Network Toolbox provides a list of validated measures of different types of stress that has been curated by experts including self-report measures and physiologically measures (https://stressmeasurement.org). Another approach would be to recruit other types of family carers, such as people caring for a child or elderly adult who are likely to be experienced some level of caregiver stress.

9.4.4 Conclusions

This chapter has provided experimental evidence of the benefit of videos and images for enhancing learning, which is consistent with the literature on dual-coding theory. The relatively large effect sizes found indicate the practical significance of the results. Parents and healthcare professionals told us videos would be helpful, but given that people are generally bad at reflecting on what might be helpful or might have helped them (Nisbett & Wilson, 1977), it was important to test whether videos helped learning in an experimental design. We did not find evidence of a benefit of the addition of videos for learning, compared to adding images and key facts, although numerical trends were in the predicted direction and the video training was rated as significantly more understandable and led to higher judgements of learning. The findings from this experiment give me confidence that videos may be helpful in the context of training parents to do medical procedures and unlike the schema-enhanced training, do not seem to have a detrimental impact on learning. Participants' self-ratings of the video materials and their performance in the test were both consistent with potential benefits of videos.

9.4.5 Next steps

There are other potential benefits of videos, besides enhancing learning for routine medical tasks, including as a means of making information more understandable and engaging. In this experiment the study materials were videos on routine care of a gastrostomy. In the next chapter I present an evaluation of a full suite of videos I have created with healthcare professionals and families on a broader range of topics relevant to gastrostomy care, including how to manage common problems, how the surgery works and advice and tips from families. These are all topics parents told us in the survey in

Chapter 6 which would be valuable. Parents might not need to 'learn' this information in the same way as they need to do learn to do routine tasks, but it is important information for preparing and supporting them to care for their child. The final chapter evaluates these videos with a sample of parents who care for children with gastrostomies and healthcare professional who support them through online surveys on acceptability of the intervention and implementation.

Chapter 10 Evaluation of training videos with families and healthcare professionals

10.1 Introduction

The ultimate aim of my thesis is to develop a package of training and support for families. The creation of a library of videos to support families throughout their journey is a key component of this. The experiment in the previous chapter gives reason to believe that educational videos are likely to benefit learning (though this needs further testing in the applied context), and are likely to be a useful addition to the existing written booklets routinely provided to families. Together the experiments suggest it is worthwhile investing time and resources into developing videos for families (which will then need further evaluation), rather than developing retrieval-based online training or schema-enhanced training materials. Alongside a team of families and healthcare professionals, I have developed 19 videos for families caring for a child with a gastrostomy: this includes videos on routine care, information about the surgery and different devices, common problems/troubleshooting and advice and tips from families. The library of videos is intended to support families from when their child is referred for a gastrostomy, to long term support at home after the surgery. This chapter presents an evaluation of the videos from the perspective of families who care for a child with a gastrostomy and healthcare professionals who support them. In these next few sections I describe how the video library was developed, and then discuss acceptability of interventions which is the focus of the evaluation presented in this chapter, and explore what else might be needed from a training and support package beyond acceptability.

10.1.1 Development of the video library

The content of the video library was influenced by findings from the incident study in Chapter 3, the interviews in Chapter 5 and by the surveys in Chapter 6. The development process was guided throughout by the views of the stakeholder group I formed to support my research: the group met formally every three months, with regular contact in between. I secured an additional grant to fund a video editor, and part-time employment of two community nurses to support the video development (https://q.health.org.uk/idea/2019/supporting-parents-to-care-for-children-with-medical-complexity/). I led the project, provided the vision and co-ordinated the work day-to-day.

Critically, parents' recommendations from the survey in Chapter 6 indicated that both healthcare professionals and families ought to feature in the videos and at least some of the videos should be filmed at home. The videos were therefore designed to feature families in the home environment as well as the various different types of healthcare professionals families interact with. The videos feature families, children's nurses from community services, a specialist surgical nurse, a surgeon and a paediatrician. The incident study in Chapter 3 demonstrated that discharge from hospital was a particularly risky period, but that there was also safety concerns longer term: the video library was therefore designed to educate families at the different stages of their journey. A key advantage of videos over verbal information from healthcare professionals, is that videos can be-watched as a refresher as needed. Videos may be particularly valuable when access to information from healthcare professionals can be difficult, such as evenings or weekends. It was clear from the interviews with parents in Chapter 5 and the surveys in Chapter 6 that the emotional impact on families needed to be acknowledged in the

videos: some of the videos were therefore designed to address how families might be feeling, and for families to hear from the experiences of other parents. The exact content and topic list for the videos was informed by the recommendations from family carers in the survey in Chapter 6 and by the views of the stakeholder group supporting the project.

The final library consisted of 19 videos: Figure 10.1 shows the full list of topics covered and Figure 10.2 shows some screenshots of images from the videos. The videos are now hosted with my collaborators at Oxford Simulation Teaching and Research Centre (OxSTaR) who are based at the John Radcliffe hospital, and used routinely with families at the JR as part of their training and support. The videos are available here: https://www.oxstar.ox.ac.uk/more/supporting-parents/watch-the-videos .

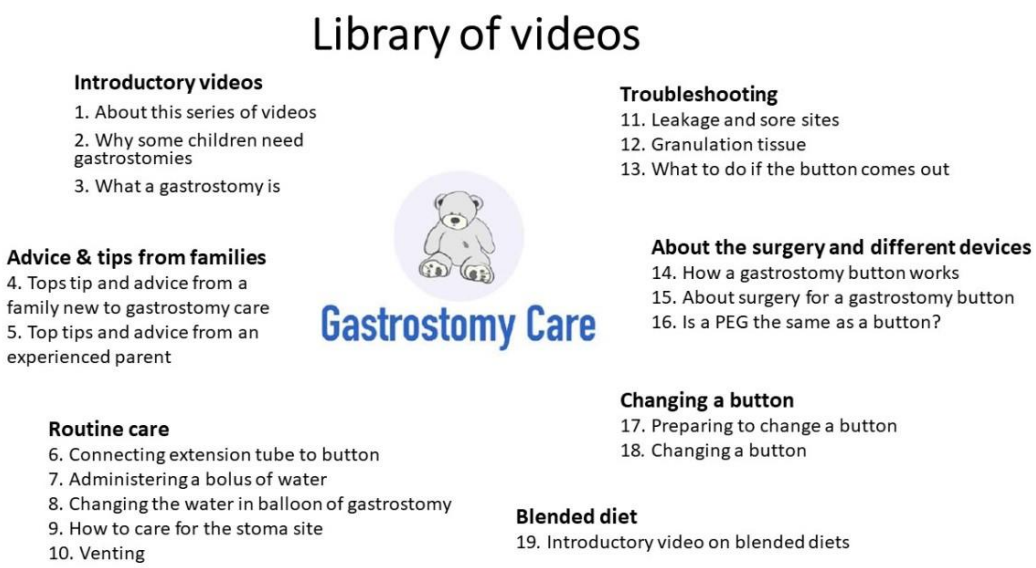


Figure 10.1 List of topics included in the library of videos for families caring for children with gastrostomies

Figure 10.2 Images from the library of videos

Throughout the development process I have informally evaluated the videos with the stakeholder group. Many of the videos have been scripted and revised by myself and the two community nurses funded to support the project. We have consulted a wide range of relevant professionals to ensure the content of the videos is appropriate and consistent with best practice. As part of the editing process members of the stakeholder group watched the videos and suggested edits, and were asked four open-ended questions: i) 'How helpful would these videos be for parents to watch and learn from?', ii) 'Do you have any concerns about any of the advice or practices in these videos?', iii) 'Is there any information missing from the videos?' and iv) 'any final comments?'. Formative assessment was critical to revising the content of the videos and the topic list (e.g. adding additional diagrams or voiceovers to help make the information clearer), and for ensuring the content is consistent with best practice guidance.

10.1.2 Acceptability of interventions

The 'acceptability' of an intervention is a necessary but not sufficient condition for effectiveness of an intervention; there is no point evaluating outcomes of an intervention until we first investigate acceptability (Sekhon, Cartwright, & Francis, 2017). Intervention implementation is often undermined by issues such as poor engagement with the intervention by recipients (in this case parents) or poor delivery of the intervention (in this case by healthcare professionals) because of factors such as lack of belief that it will be of benefit (Craig et al., 2008). Successful implementation of the videos depends on the acceptability of the intervention to both intervention deliverers (i.e. healthcare professionals who support and train parents) and recipients (parents). The concept of acceptability is widely used in the literature on intervention development and implementation but is often not explicitly defined, and is used by researchers to mean different things (Sekhon et al., 2017). One relevant definition given in a review on the concept of acceptability is: "*A multi-faceted construct that reflects the extent to which people delivering or receiving a healthcare intervention consider it to be appropriate, based on anticipated or experienced cognitive and emotional responses to the intervention."* In the review six components of acceptability are defined: affective attitude, burden, perceived effectiveness, ethicality, intervention coherence, opportunity costs, and self-efficacy (Sekhon et al., 2017). This definition of acceptability has informed the design of survey questions used in this chapter to evaluate the videos: this definition was chosen as it is broad, based on a review of the literature and the concepts are appropriate to my intervention and population. Before we can further investigate the effectiveness of the videos, we must explore the acceptability of the intervention with families and healthcare professionals.

An effective training and support package ought to improve outcomes such as parental knowledge, skills and confidence. Improvements in parental knowledge, skills and confidence may lead to fewer callouts to community teams or visits to A&E, and potentially also reduce rates of complications and harm in children. Before we can begin to assess any of these outcome measures, we must first ensure our library of videos is acceptable, especially to families who are the end-users. It is important also that healthcare professionals perceive the videos to be useful and appropriate for use in routine practice. This involves understanding such issues as how and when each video might be used by parents, what guidance is needed, any potential risks and how clinical staff should introduce the video library to patients. A necessary next step therefore is to evaluate the library of videos with families and healthcare professionals as part of the piloting and early implementation of the videos. If the videos are deemed to be acceptable to families and healthcare professionals, future studies are then needed to evaluate long-term outcomes, such as ratings of parental skill or knowledge, and any reductions in demand on health services (e.g. callouts to hospital and community teams) or rates of complications or errors.

10.1.3 Study aims

This chapter therefore evaluates the videos with a sample of parents who care for children with gastrostomies and healthcare professionals who support them. The aims are:

1. To evaluate the acceptability of the library of videos with a large sample of families and healthcare professionals who care for children with gastrostomies,

including the perceived impact/benefits of the videos, and satisfaction with the content and presentation of the videos.

2. To explore healthcare professionals' and families' views on how to make best use of the videos in practice

10.2 Methods

10.2.1 Survey design and development

I designed a mixed-methods survey, with two similar but slightly different versions adapted for families and for healthcare professionals. The family version and the healthcare version both had a roughly even number of qualitative and quantitative questions. The qualitative data was intended to help support, illustrate and expand the quantitative data (Terry & Braun, 2017). The surveys were designed with the intention that the results would be practically useful to the clinicians implementing the videos across our region, and also potentially for other regions who were interested in using the videos.

In the initial exploratory stage of development, I reviewed the literature on evaluating medical education interventions with families and evaluating instructional videos, including different rating scales and definitions of acceptability. The surveys were drafted, piloted and revised in consultation with parents, children's nurses and paediatricians from the community and a paediatric gastrointestinal surgeon. The team were asked to comment on the suitability of the questions, readability and length, and to consider how the surveys could inform the implementation of the videos. Recruitment strategies were developed based on advice from parent representatives, clinicians and my supervisors. The evaluation of the videos was approved as a service evaluation by the

Research and Governance Committee at Oxford University Hospitals NHS Foundation Trust and the University of Oxford. The committee classified the study as a service evaluation (rather than a research study) and it was therefore not necessary to apply for research ethics from the NHS (HRA approval) or the University of Oxford.

10.2.2 Survey content

The surveys consisted of four sections: i) information about the participants, ii) watching a sample of videos, iii) evaluating the content of the videos and iv) using the videos in practice. Most of the questions were the same for families and healthcare professionals, with some minor adaptations for the two different audiences which are explained below.

10.2.2.1 About the participants

Families were asked about their relationship to the child, (e.g. mother), how old the child was, what types of gastrostomy device their child had, how long ago their child's surgery was (or if the child was on the waiting list for surgery). Healthcare professionals were asked what their job role was and if they were involved in teaching parents or staff about gastrostomy care.

10.2.2.2 Watching a sample of videos

All participants were asked to watch a sample of six videos which were selected to cover a range of different topics, with a comment box below each video. Participants were also shown the full list of video topics included in the library (see Figure 10.1). I did not ask participants to watch all 19 videos as this would take around an hour to do and would likely limit the number of participants I could recruit. I also felt it was important to control the number of videos and which topics participants watched before answering the evaluation questions, so randomising participants to watch different videos would have

made interpreting the results difficult. The decision was therefore taken to ask participants to watch six representative videos: 'why children need gastrostomies', 'top tips and advice from a new family', 'changing the water in the balloon', 'about the surgery', 'what to do if the button comes out' and 'granulation tissue'.

10.2.2.3 Evaluating the content of the videos

Participants were asked to rate statements assessing the acceptability of the videos on a 5-point Likert scale from 'strongly disagree' to 'strongly agree'. The questions were designed to capture different components of acceptability: burden (e.g. "the videos are an appropriate length"), experience (e.g. "the information in the videos is easy to understand"), perceived effectiveness (e.g. "the videos will help prepare parents to care for their child's gastrostomy") and intention ("I would recommend these videos to parents"). Participants were also asked a few open-ended questions on what they liked about the videos, what they found most helpful, what could be improved and any additional topics they wanted to see covered. They were also asked whether they had learnt anything new from the videos, and to describe what they had learnt.

10.2.2.4 Using the videos in practice

Families and healthcare professionals were asked how they would want to make use of the videos. They were asked to rate at which time points parents should watch the different videos: before surgery, around the time of surgery, in the first few weeks at home or after the child had had their gastrostomy for several months or years. There was also a box for further comments. Healthcare professionals were also asked various open-ended questions about how they would use the videos in their practice, and whether they would also be useful for staff training. Both families and healthcare professionals

were asked for any organisations we should contact to make them aware of the videos, and where they would most like the videos to be hosted. They were also asked for any suggestions for further topics to include in the future.

10.2.3 Sampling and recruitment

10.2.3.1 Family carers

For the family carer survey the inclusion criteria was any parent or family carer who provides gastrostomy care to a child or young person at home or has a child on the waiting list for gastrostomy surgery. By family carer, we included any unpaid carer (parent, relative, friend) who actively participates in caring for a child or young person with a gastrostomy. To take part family carers needed to be at least 18 years old. Participants received a £10 voucher as an incentive for taking part.

Families who completed the survey in Chapter 6 and agreed at the time to be contacted again to rate the videos, were invited to take part in the survey (*n* = 102). All of these families had at least one year's experience caring for their child's gastrostomy. In order to recruit some additional families who were new to gastrostomy care, the surgical lead for the region invited some families on the waiting list for gastrostomy surgery or who had recently had surgery at the John Radcliffe hospital to take part. Our parent representatives contacted a few relevant charities and leads for closed Facebook groups to help recruit families who had recently had gastrostomy surgery. Due to the Covid-19 pandemic, far fewer surgeries for gastrostomies have taken place compared to usual.

10.2.3.2 Healthcare professionals

In order to take part in the healthcare professionals' survey, participants needed to be a healthcare professional who supports children and young people who have gastrostomies

(e.g. community nurses, hospital-based children's nurses, surgical feeding teams, paediatricians, dieticians, respite and school staff, registrars and junior doctors etc.). Participants received a £10 voucher as an incentive for taking part.

I aimed to recruit a range of different types of healthcare professionals who support families with gastrostomies, including community children's nurses (CCNs), specialist surgical nurses, paediatricians, surgeons and registrars, dieticians and other community professionals (e.g. hospice and respite staff, school nurses). The surgical lead for gastrostomies in the Thames Valley region compiled a list of relevant healthcare professionals (*n* = 58) who were invited by email to take part. I then contacted three other regions to be involved in the evaluation, to explore whether the videos might be useful in practice outside of our region. The three regions were asked to contact a minimum of 10 healthcare professionals who support families with gastrostomies in their region.

10.2.4 Analysis

Participants were included if they completed the full survey defined as viewing all pages of the survey, and completing at least 90% of the quantitative questions. Some of the family carer responses were excluded as probable spam responses, based on an assessment of the open-ended responses (these occurred after one of the charities posted the link on Twitter). Descriptive statistics were computed for all close-ended questions, using SPSS Statistics 25. Participants who did not complete the full survey were excluded. The open ended questions were coding in NVivo 12 using inductive content analysis, to group responses based on surface level of meaning (Elo & Kyngäs, 2008). Answers were coded line by line, and grouped into categories emerging from the data. These were summarised in the text and illustrated with quotes from participants. In the

first section of the survey (the evaluation of the content of the videos) my analysis focuses primarily on family carers' responses, with some feedback from healthcare professionals included, since families are the primary audience for the videos. Conversely the second section on using the videos in practice focuses primarily on the responses of healthcare professionals with some additional feedback from families, since it is healthcare professionals who lead on implementing the videos.

10.3 Results

10.3.1 Participants

There were 342 responders who viewed the first page of the survey. Forty-two family carers completed the full survey (defined as viewing all pages and completing at least 90% of the quantitative questions at a minimum). The majority of family carers were mothers (*n* = 36, 86%), five were fathers (12%) and 1 was another family member. The age of the children ranged from 0 to 16 years: 12 (29%) were 0-3 years old, 19 (45%) were 4-6 years and the remaining 11 children (26%) were between 10 and 16 years old. Some of the family carers were new to gastrostomy care and some were very experienced. Two (5%) of the families were on the waiting list for gastrostomy surgery, for four families (10%) the surgery was less than a year ago, for 11 (26%) it was 1-2 years ago, for 16 it was 3-4 years ago (38%) and for 9 (21%) the surgery was 5 years ago or longer.

Thirty-three healthcare professionals completed the full survey (defined as viewing all pages and completing at least 90% of the quantitative questions at a minimum). Sixty-two responders viewed the first page of the survey. There was a mixture of different professionals who completed the survey: 7 paediatricians, 6 CCNs, 6 dieticians, 4 hospital nurses (e.g. specialist surgical nurses, children's ward nurses), 4 other community-based

professionals (e.g. respite services, schools), 3 surgeons or surgical registrars and three classified as other relevant professionals (1 nursery nurse, 1 practice development nurse and 1 doctor in training from overseas). A majority (67%) of these professionals indicated they had been involved in teaching parents to care for a gastrostomy during their career. A similar proportion (61%) had also been involved in teaching staff to care for a gastrostomy. Two-thirds of the healthcare professionals (*n* = 22) were from the Thames Valley region, and one third (*n* = 11) were from another region (East of England, London or South Wales).

10.3.2 Evaluating the content of the videos

This section mostly focuses on the feedback from family carers who are the primary users of the videos. Some sections also include feedback from healthcare professionals where relevant.

10.3.2.1 Participants' ratings of the training videos

Both parents and healthcare professionals perceived the video library as a valuable resource for parents, and indeed professionals, and strongly supported the use of the videos in practice. As Table 10.1 and Table 10.2 show, nearly all statements were rated as 'strongly agree' or 'agree' by over 90% of family carers and over 90% of healthcare professionals. Notably 76% of family carers and 91% of healthcare professionals 'strongly agreed' that they would recommend the videos to parents, and 83% of family carers and 88% of healthcare professionals 'strongly agreed' that the videos would be helpful to families new to gastrostomy care (with the remaining agreeing). Ratings for the statement "the videos would be helpful to experienced parents" were lower, with 64% of family carers and 72% of healthcare professionals agreeing or strongly agreeing. There

were a small number of family carers who disagreed with the statement "I have no concerns about the accuracy of advice given in the videos". From the comments, these concerns seem to relate to small differences in practice across the country, for example some families commented that button tube pads were not recommended in their area or using enplug stoppers if the button comes out: "*Some medics are vastly against tube pads or indeed using maxitrol so it could be made clearer that opinions will vary*."

Table 10.1 Ratings of statements evaluating the content of the training videos by family carers

	Strongly Agree N (%)	Somewhat Agree N (%)	Neither agree or disagree N (%)	Somewhat disagree N (%)	Strongly disagree N (%)	Missing N (%)
The information in the videos is easy to understand	34 (81%)	7 (17%)	0	0	0	1 (2%)
There is a good mixture of healthcare professionals and families in the videos	36 (86%)	4 (10%)	1 (2%)	1(2%)	0	0
I have no concerns about the accuracy of advice given in the videos	23 (55%)	11 (26%)	3 (7%)	2 (5%)	2 (5%)	1 (2%)
The videos are an appropriate length	29 (69%)	11 (26%)	1 (2%)	0	0	1 (2%)
There is a good range of topics covered	32 (79%)	9 (21%)	0	0	0	0
The videos will help prepare parents to care for their child's gastrostomy at home	30 (71%)	10 (24%)	1 (2%)	1 (2%)	0	0
The videos will help families to feel more confident	32 (76 %)	9 (21%)	1 (2%)	0	0	0
The videos will be useful to families new to gastrostomy care	35 (83%)	7 (17%)	0	0	0	0
The videos will be useful to families who are more experienced at caring for their child's gastrostomy	11 (26%)	16 (38%)	9 (21%)	3 (7%)	3 (7%)	0
I would recommend these videos to parents	32 (76%)	9 (21%)	1 (2%)	0	0	0

Table 10.2 Ratings of statements evaluating the content of the training videos by healthcare professionals

	Strongly Agree N (%)	Somewhat Agree N (%)	Neither agree or disagree N (%)	Somewhat disagree N (%)	Strongly disagree N (%)	Missing N (%)
The information in the videos is easy to understand	28 (85%)	5 (15%)	0	0	0	0
There is a good mixture of healthcare professionals and families in the videos	27 (82%)	5 (15%)	1 (3%)	0	0	0
The information in the videos is consistent with best practice guidance	20 (61%)	10 (30%)	2 (6%)	1 (3%)	0	0
The videos are an appropriate length	22 (67%)	10 (30%)	0	0	0	0
There is a good range of topics covered	25 (76%)	7 (21%)	1 (3%)	0	0	0
The videos will help prepare parents to care for their child's gastrostomy at home	25 (76%)	8 (24%)	0	0	0	0
The videos will help families to feel more confident	28 (85%)	5 (15%)	0	0	0	0
The videos will be useful to families new to gastrostomy care	29 (88%)	4 (12%)	0	0	0	0
The videos will be useful to families who are more experienced at caring for their child's gastrostomy	10 (30%)	14 (42%)	8 (24%)	1 (3%)	0	0
I would recommend these videos to parents	30 (91%)	3 (9%)	0	0	0	0
I would recommend these videos to my colleagues	26 (79%)	7 (21%)	0	0	0	0

10.3.2.2 General reflections on the video library

Participants offered many reflections when asked what they liked most about the videos. The main themes are highlighted below. Appendix 15 summarises the comments on individual videos in more detail.

10.3.2.2.1 Ease of understanding

Most family carers and healthcare professionals commented on how easy the information was to understand, and felt the videos were short and to the point. A few participants commented on the simplicity of the language and the useful diagrams and summaries of key points. One family carer, for example, commented on how useful the 3D models were in the surgery video: "*When we had our consultant with the surgeon he drew a few scribbles on a piece of paper to explain it - however in the video you used actual models to show it.*"

10.3.2.2.2 Balance of parents and healthcare professionals

Many of the family carers and healthcare professionals commented on the mixture of families and healthcare professionals featured in the videos. For example one family carer commented "*I think the balance between parents/carers having first-hand experience and also clinicians is really important and done very well.*" Families appreciated seeing other families in the home environment: "*I like that parents were used in this who have experience – it's reassuring for new parents to see how normal this new normal is.*" Some family carers and healthcare professionals commented on the range of healthcare professionals involved from the community and hospital, with one Oxford-based family commenting, "*Lovely to see the professionals that we know from the hospital involved as adds 'comfort'*."

10.3.2.2.3 Perceived emotional impact of the videos

Some family carers commented on the emotional impact of the videos. A sense of feeling empowered was a common theme. For example one parent with a child on the waiting list for surgery said: *"This was so normalising and reassuring. It helped us to imagine our lives when our daughter has her button in place. They were incredibly empowering."*

Another family new to gastrostomy care commented that *"It felt like we were having a consultation/conversation in person. Having videos was dramatically better than having only a printed leaflet."* A few family carers commented on how reassuring they found some of the videos, especially the advice and tips from a new parent video: "*I found this video really moving. It was helpful and reassuring to hear about the emotions involved for this family. It made the whole process seem a bit less daunting and more real*." Some healthcare professionals also commented on the potential emotional benefits of the videos: "*Parents and carers like to be able to access information in a way that they won't feel judged and that they can re-watch multiple times. Having videos means that they will not have to contact the community teams/hospital teams for simple questions and this will undoubtedly help to empower them."*

10.3.2.3 Suggested improvements to the videos

Most of the comments from family carers and healthcare professionals on what to improve were minor suggestions. Some suggestions related to the quality of the videos, e.g. the sound quality, or the professionals in the videos looking a little "*stiff".* There were a few comments with suggestions for adding further specific details, or content, or highlighting small differences in practice between what was in the videos and what a family does/or is recommended in their region. A few of the family carers requested more diversity in the families featured, e.g., including Dads. As one family carer points out, families' journeys differ and all children are different: *"I think there should be many more videos involving parents who have to deal with these situations every day especially because every child is different."*

10.3.2.4 Learning from the videos

Participants were asked whether the videos had aided their own learning. For the family carers, 5 (12%) responded “yes a lot”, 22 (53%) responded “yes a little” and 14 (33%) said the videos had not aided their own learning. For the healthcare professionals, 5 (15%) responded “yes a lot”, 21 (64%) responded “yes a little” and only 6 (18%) said that videos had not aided their own learning.

The two parents with a child on the waiting list for surgery learnt a lot from the videos. One of these parents commented “*We are familiar with NG tubes but didn't know anything about PEGs/buttons, except they were some kind of surgically installed port in the stomach. We now feel like we understand the subject and are in a much better position to ask relevant questions in clinic*.” The other parent commented “*Although I had read through the leaflets I think having the videos allows us to visualise what the different terms mean, which is so helpful for making sense of, and retaining, the information. I understand better how the surgery works, what procedures are needed to care for the button and the stoma, and I'm more comfortable with the terminology.”*

Even some very experienced family carers described learning new things from the videos, or finding the videos a helpful reminder. For example one experienced parent said: “*Great idea, could really have used these 10 years ago but even now they’re really useful for a reminder as parents tend not to get any updated training.”*

Participants were asked to reflect on which particular videos they found most helpful. Videos frequently mentioned by family carers and healthcare professionals included the video on granulation tissue (a troubleshooting topic) from the specialist surgical nurse, the video on how the surgery works and the video on what to do if the button comes out.

Healthcare professionals valued the advice on granulation tissue from the area specialist: *"Granulation is always a difficult one to resolve so good to know the favoured 5 steps the Oxford CNS [clinical nurse specialist] suggests with confidence."* A few healthcare professionals also commented on learning something from the families in the videos: "*The testimony from the mother of a girl with gastrostomy was very insightful, especially how she explained the gastrostomy to her daughter in the form of a story*."

10.3.3 Using the videos in practice

This section primarily focuses on the perspective of healthcare professionals as they are responsible for the organisation and delivery of services, with some data and reflections from families where relevant.

10.3.3.1 How the videos might fit within the existing pathway

Participants were presented with different topic areas for the videos and asked to rate when a particular group of videos would be most appropriate to watch: i) "when referred to hospital team for a gastrostomy", ii) "around the time of surgery", iii) "in the first few weeks at home after surgery", iv) "after child has had gastrostomy for a few months or years" or v) "not sure". Participants could select more than one time point if they felt that was appropriate. Family carers and healthcare professionals broadly agreed on which videos would be most appropriate to watch when. Table 10.3 shows a diagram of which topics were rated as more appropriate to watch when. Some topics are listed under more than one time point. Each topic consists of 1-4 individual videos (see Figure 10.1). Appendix 16 provides more detailed data on participants' responses.

Table 10.3 Library of videos illustrating which videos will be most helpful to parents at the different stages of their journey. This is based on the ratings by healthcare professionals and family carers in the survey.

**Dark green illustrates the most helpful times and pale green illustrates other times when the videos might be helpful.*

	When referred to surgical team	Around the time of surgery	First few weeks at home	After child has had a gastrostomy for a few months or years
Introductory videos				
About the surgery & different devices				
Routine care				
Troubleshooting				
Changing a button				
Blended diet	**To know blended diet is an option*			
Advice & tips from other families				

The introductory videos and videos about the surgery and different devices were rated as most appropriate to watch when referred to the hospital team for a gastrostomy, and potentially also around the time of surgery. Videos on advice and tips for other families were rated as most useful around the time of surgery and in the first weeks after surgery, and potentially also upon referral to the hospital team. Videos on routine care of a

gastrostomy were felt to be most appropriate to watch around the time of surgery and in the first few weeks at home after surgery. The troubleshooting videos were rated as most helpful in the first few weeks at home after surgery, as well as potentially around the time of surgery and longer term after the child has had their gastrostomy for a few months or years. Changing the button was thought to be best watched in the first few weeks at home after surgery or after the child has had their gastrostomy for a few months or years. There was comparatively less agreement on when to watch the video on blended diet. Blended diet is not appropriate for all children. Over half of family carers rated the blended diet as appropriate to watch upon referral to the hospital team for surgery, perhaps to know that blended diet was an option. As one family carer comments, "w*e are huge fans of blended diet so would be keen that it was introduced at an early stage, but we also understand that every journey is different and it will not suit every child or family."* Healthcare professionals had slightly different views on when the blended diet video should be watched: nearly three quarters of healthcare professionals said it would be most appropriate to watch the blended diet video after a child has had their gastrostomy for a few months or years.

A few parents indicated that they wanted to watch most of the videos before the surgery, but this was not the general consensus: "*I guess it depends on how the parents feel I personally would of found these videos helpful before operation but guess some parents may find them overwhelming*." Conversely another parent indicated that they would not want to watch all the videos before surgery as this would be information overload: "*I think too much information overload for the trouble shooting/care if prior to surgery, as parents would be focussing on that at that point in time."* What is appropriate for one family may not be appropriate for another; there will be individual circumstances which

affect which videos will be most helpful when but these data gives some indication on where the different videos might best fit in the patient pathway.

10.3.3.2 Reflections from healthcare professionals on using the videos in practice

Healthcare professionals were asked to reflect on how they might use the videos in their practice. Some participants reflected on how the videos might fit within the existing pathway for training families: "*Concise, clear videos from a range of professionals that can be used when discussing the decision about a referral for a gastrostomy and can be used following gastrostomy placement."* One healthcare professional gave a detailed explanation of how they felt the videos would fit within the existing pathway: "*Direct parents to introductory videos, advice from parents and surgery videos when discussing need for placement of gastrostomy. Routine care, troubleshooting, changing a button on discharge from JRH [John Radcliffe hospital] following placement. Blended diet video useful resource to direct parents to when they approach the dietitian to state they are interested in this method of feeding as shows some of the practical aspects involved."* One participant commented on the usefulness of the videos for educating parents prior to the surgery: "*The leaflets we have currently are pants, and this will be much better. We have also had difficulties due to recommissioning of CCNs in getting them to see and show information to the families in advance of the first appointment, which historically has been really helpful. I suspect this will be an excellent resource."*

Notably nearly all the healthcare professionals commented on the value of the videos for staff training as well as for training families. For example one commented that the videos "*help to standardise practice*", amongst professionals as well as families. The benefits of videos rather than giving information verbally or in face-to-face teaching sessions is that

the information is consistent, which helps to standardise practice. Conversely the disadvantage of videos is the content cannot be adapted to individual children and families and cannot show every safe way of doing procedures.

Other suggestions for additional topics to cover in the videos included practical issues around managing supplies and reuse of equipment, different types of devices and setting up feeds and using feeding pumps. One healthcare professional commented "*It would be great to see similar videos for other devices, for example a tracheostomy*".

10.3.3.3 Potential dangers and risks

Participants were asked to comment on any potential dangers or risks. Most respondents indicated they did feel there were any dangers or risks: *"Not that I can think of. The information is well-balanced, and it acknowledges risks and challenges while still being reassuring. I like that it doesn't offer false reassurance."* There were a few comments about differences in practice across the country, for example one healthcare professional noted: *"That other areas of the country do things slightly different and that is not always clear in the instruction videos."* A few healthcare professionals and families mentioned the risk that families might watch the videos and not also seek out training: "*Is there a risk people may watch a video rather than "bother" a professional before being trained, rather than as an aide memoire?".* Several healthcare professionals commented on the importance of using the videos alongside face to face training, and not to replace it, or assume that if a parent has watched the video they will have understood it all: "*The videos may deskill HCPs or give false confidence that parents understand the risks of a gastrostomy. It is important for HCPs to follow these videos up with sound counselling and use the videos as visual reminders."* A few comments also related to the risks of

overwhelming families with information: *"It could come across as a bit scary or overwhelming but not through any fault of the videos and it is all important and relevant information to know to enable parents to make an informed decision and get the most out of a consultation."* It is important to remember that the video library is there to empower parents and supplement face-to-face training and should not be used as a replacement.

10.4 Discussion

10.4.1 Summary

The survey data presented in this chapter demonstrates that the videos are clearly acceptable and valued by both families and healthcare professionals. Nearly all participants agreed the videos would help families to feel confident, and would help prepare families to care for their child's gastrostomy at home (measure of perceived effectiveness of the intervention). Over 90% of family carers and healthcare professionals would recommend the videos to other parents (measure of intention). In terms of the content of the videos, over 90% of participants agreed that the videos were an appropriate length (minimal burden of the intervention), covered a good range of topics and featured a good mix of healthcare professionals and families. Several families commented that they found the videos empowering (affective attitude). The videos were also rated by a majority as also useful for more experienced families, either as a refresher or to help with specific troubleshooting issues as needed. The evaluation has provided a clear indication of which videos might be most appropriate to watch at different time points in families' journeys, and how they might be used in practice. The videos may also have a role in staff training and helping to standardise practice. The video library serves as a useful addition to the existing training families receive.

10.4.2 Refinement of the video library

Participants suggested a number of small technical improvements to the videos, such as concerning sound quality, camerawork and confidence of the speakers. More professional versions of these videos could be created in the future with more funding. Another key theme was differences in practice: the evaluation has revealed many small differences in what is taught to families between different professionals, organisations and regions. It is impossible to create videos which cover all these differences, and the risk of making the information in the videos too general is that they become less useful. Primarily the videos have been created with and for families and professionals in the Thames Valley and we are confident they are consistent with best practice in our region. However, the evaluation data from professionals and families outside our region suggests the videos have utility in other parts of the country. We have recently filmed an extra video explicitly discussing differences in practice to reassure families that what is shown in the videos is a safe way of doing things, but also emphasising the need to follow the advice of the healthcare professionals who support your family. The videos are there to supplement existing face-to-face training, and may well help to educate professionals too and help standardise the information provided.

10.4.3 Strengths and limitations

One strength of the sample of family carers is it included some families relatively new to gastrostomy care and some who were more experienced. More experienced families are better able to reflect on what is needed at the different points in their journey, however it was also important to capture whether the videos were acceptable to families at the start of their learning journeys. The sample also included a variety of different types of healthcare professionals who support children with gastrostomies.

One limitation is that I did not collect demographic data on the families so cannot tell the socio-economic, health literacy or ethnicity of families. It is impossible to know how selection bias affected the results: I may have recruited families who are more engaged in their child's care or families who felt unprepared and sought help through Facebook groups and charities. The sample of healthcare professionals did not include many professionals from outside the Thames Valley region; we would need to recruit more participants from other regions to be sure the videos are acceptable to other areas of the country.

10.5 Conclusions

This chapter has provided encouraging data on the acceptability of the videos with both family carers and healthcare professionals, as well as guidance on how the videos can be best used in practice. The videos are likely to be helpful as part of a wider training and support package and can support families at different time points in their learning journeys. The videos were intentionally designed to feature families and a range of different healthcare professionals and to provide emotional support to families as well as practical advice. Developing the videos has been a real collaboration between researchers, families and healthcare professionals from the hospital and community. However more is needed in a training and support package beyond the videos. The next chapter is a discussion chapter which describes what is needed in a full package of training and support for parents caring for a child with a gastrostomy, drawing on findings from the different sections of my thesis. The chapter details the theoretical underpinnings of the package and the various different components, of which the videos are a crucial part.

Chapter 11 What is needed in a wider package of training and support

My thesis finishes with two discussion chapters. This chapter discusses the recommendations from across my thesis for training and supporting parents, and the final chapter discusses wider implications and reflections on my thesis. In this chapter I present recommendations for what a full package of training and support ought to look like, based on findings from across my thesis. The library of videos evaluated in the previous chapter is a core part of a package of training and support for parents caring for a child with a gastrostomy, but is only one component of what parents need. The videos provide parents with the core medical information they need, and are also intended to support them emotionally and long-term, e.g. helping families to troubleshoot when problems arise. However, parents also need hands on practice as part of their training, and further resources to support the whole family emotionally and long-term. This chapter first describes the need for this wider package of training and support and the research and theoretical underpinnings of the package. I then describe the core components of the package and some of the practical steps towards implementation taken across the Thames Valley region. The package of training and support described in this chapter focuses on gastrostomy care, however many of the recommendations will be relevant to training for other medical procedures families are asked to perform at home.

11.1 The need for a wider package of training and support

The balance of benefits and risks of families performing medical procedures at home are not static, but hugely dependent on how well families are trained and supported. As we saw in the earlier chapters of my thesis, training and support for families is often ad hoc, and is not currently addressed from a system perspective across the health and care

system. Many families feel anxious and isolated, and there is evidence of some children coming to harm unnecessarily (as we saw in the incidents in Chapter 3). We need to design a package of training and support with and for families, starting from their needs, and then fitting the package around existing services. Training and support is the responsibility of multiple different teams across hospital and community services. We have designed our package around the needs of parents, both in the short and long-term, rather than starting from the point of view of a hospital or community team who support parents at specific points in their journey. Preparation and support for parents caring for medically complex children needs to be given comparable attention than is given to training and supporting healthcare professionals. Whilst there are pockets of good practice across the country, there is a real need to provide a vision on what good training and support might look like across the system.

11.2 Existing training programmes

This next section describes some existing training programmes, and how these have informed the development of the training and support package described in this chapter. There are very few training programmes specific to gastrostomy care reported in the literature, although a number of publications have cited the importance of improving training for parents caring for children with feeding tubes (e.g. Dekonenko et al., 2020; Evans et al., 2012). One hospital-based training programme for parents in the US reported some improvement in outcomes, such as the proportion of parents who knew what to do if the gastrostomy device came out and an improvement in the knowledge of nurses who trained parents (Kirk, Shelley, Battles, & Latty, 2014). The programme mostly focused on upskilling the nurses who train parents and introducing more written information for parents and staff. The authors discuss the potential to reduce the number

of visits to the emergency department for gastrostomy device problems, but the data was not available.

Practical video-based training interventions for family caregivers on a range of different medical procedures are reported in the international literature, although there has been limited evaluation of their impact. For example, a web-based video education has been requested by families caring for children with tracheostomies in the US and a wide range of videos have since been created (Callans, Bleiler, Flanagan, & Carroll, 2016). The National Tracheostomy Safety Project in the UK has also recently produced a range of educational videos targeted at healthcare professionals, with some videos specifically targeting parents caring for children with tracheostomies (www.tracheostomy.org.uk/resources/videos). A large project in the US by the AARP Public Policy Institute has created a suite of educational videos for family caregivers on a range of common medical and nursing tasks (https://www.aarp.org/ppi/initiatives/home-alone-alliance/family-caregiving-videos/). These educational videos have been reported in the academic literature, with papers targeted at nurses in the form of instructional guides for teaching families to manage specific medical procedures at home (Fields, Whitney, & Bell, 2020; Kirkland-Kyhn et al., 2018). To the best of my knowledge, the educational videos described above have not been formally evaluated in the literature, in terms of whether they help learning or their impact on families or the rate of complications in patients, although many of the videos have been viewed by large audiences on YouTube.

There are also some emerging examples of training programmes based on simulation practice with patients and families. Some of these programmes have been evaluated and

shown some impact on rates of complications and even mortality, for example evidence of simulation training reducing centre-line infections in parents caring for children with cancer (Heiser Rosenberg et al., 2017) and evidence of simulation training for parents reducing mortality for children on ventilators (Stanley, Battles, Bezruczko, & Latty, 2019). Simulation-based mastery learning has been used for patients and caregivers for ventricular assist devices (VAD), and a measure developed for assessing skills (Barsuk, Harap, et al., 2019; Barsuk, Wilcox, et al., 2019). Some of these training programmes suggest impressive real-world improvements in outcomes can be achieved through simulation training with families, although the sample sizes in the studies are small.

Evidence from the literature suggests that videos and simulation practice are popular interventions for improving training for families who do medical procedures at home. The simulation studies in particular have been able to demonstrate some impressive outcomes. Training programmes focusing on upskilling nurses who train families may also have some benefit, though these can be difficult to evaluate (Berman et al., 2017). The package of training and support in this chapter draws on findings from the literature described above, but goes beyond what already exists to consider what is needed across the whole patient pathway from referral to a gastrostomy to long-term support in the community, rather than focusing simply on training provided during a short hospital stay which is the focus of many of the studies described above. Our package of training and support is also intended to meet families' emotional needs as well as teaching the practicalities such as routine care and troubleshooting issues. Critically our package of training and support is designed with and for families, with the responsibility for training and support shared across multiple different services (surgical team in hospital, CCNs, dieticians and paediatricians who refer the child for a gastrostomy).

11.3 Theoretical and research underpinnings of the training package

Before describing the package in detail, this section reflects on the theoretical underpinnings of the training package from the psychology and medical education literature, and findings from different chapters in my thesis. Key concepts that have guided the development of these recommendations include dual-processing theory, the spacing effect, deliberate practice and simulation training. These effects were discussed in more detail in Chapter 2 and in the experimental chapters (Chapters 7-9).

11.3.1 Acquiring knowledge

In my thesis I explored how we might improve the knowledge acquisition stage of learning. Chapter 2 explored a range of factors which can benefit the encoding of information. Later in my thesis I conducted a series of experiments exploring different forms of training that may improve learning and memory for medical information about caring for a gastrostomy. The experiments suggest that supplementary videos and images are likely to be beneficial, and more so than retrieval practice or schema-enhanced training, which are both widely reported to benefit learning in the psychology and education literature. The benefits of videos and images are consistent with dual-processing theory, i.e. that multiple representations of the same information enhances memory for the information provided the accompanying visual representations are informative and carefully constructed (Mayer et al., 1990). In Chapter 10 I found that our instructional videos are acceptable and highly valued by parents and healthcare professionals. Data from the experiment in Chapter 9 suggests videos can benefit learning when compared again studying written information. A package of training and support ought to make use of videos and images as a way of delivering core information on a range of topics including routine care and troubleshooting. I found limited benefit of

testing and retrieval practice as part of training in Chapters 7 and 8, which suggests resources are better invested in images and videos, rather than focusing on implementing more testing into training, although we did find evidence of some metacognitive benefits of testing.

11.3.2 Simulation training and deliberate practice

Simulation training and deliberate practice also ought to be a core part of training. Whilst simulation practice has not been explored in experimental studies in my thesis, it is a likely to be useful for developing the necessary motor skills. Simulation training (typically involving practicing skills or scenarios using mannequins/dolls) is now widely used for training medical professionals and its benefits for skill development are supported by a large body of evidence in the medical education literature (McGaghie, 2012; Motola et al., 2013). Simulation practice is underpinned by the psychological literature on deliberate practice which is thought to be useful both for developing new skills and maintaining them (Ericsson, 2004; Ericsson et al., 2005). Simulation training offers opportunities for repeated deliberate practice which do not require practicing on the patient (Motola et al., 2013). Findings from the surveys in Chapter 6 show that most parents viewed simulation practice as valuable. For these reasons, hands-on practice using models/equipment is a key element of the training package described in this chapter.

11.3.3 Spacing out learning

The psychology literature suggests spacing out learning is likely to be beneficial, both in experimental studies (Smith & Scarf, 2017) and applied contexts such as surgery and education (Cecilio-Fernandes et al., 2018; Roediger & Pyc, 2012). Shorter hospital stays are increasingly advocated for gastrostomy surgery, including same day discharges

(Dekonenko et al., 2020), meaning that there is little time to train parents during the hospital admission which really limits opportunity for spacing out information and for repeatedly practicing skills and building confidence. It is really important therefore that training begins in the community prior to the hospital admission. We know from earlier studies in my thesis (e.g. the interviews in Chapter 5 and the survey in Chapter 6) that parents are often stressed during hospital admissions and in the first few weeks at home post-surgery: the use of videos means parents can access information and demonstrations in their own time (and can watch them repeatedly) reducing the potential detrimental impact of stress on their learning. The use of videos which parents can watch at their own pace, and return to as necessary, is supported by the benefits of spacing out learning. There will also be large individual differences in what is acceptable to families in terms of how their learning is spaced out, which will probably be affected by factors such as the level of stress they are experiencing. The need to space out training is a key principle of the training package.

11.4 How the recommendations were developed

The recommendations in this chapter have been informed by a range of proven strategies from the psychology and medical education literature on how people learn and develop expertise (as discussed in Chapter 2 and in the experimental chapters), as well as by existing training interventions described in the literature. Critically the recommendations draw upon the experiences of families in Chapters 5 and 6 who care for children with gastrostomies and other types of medical needs and are also informed by the safety concerns of healthcare professionals described in Chapters 3 and 4. The recommendations have been discussed extensively with the stakeholder group supporting my research. This multidisciplinary group have an understanding of the whole

pathway from referral for a gastrostomy to long-term support needs in the community. Members include parents, a paediatrician, the gastrostomy surgeon and specialist nurses from the hospital, CCNs and nurses from respite and palliative care services. We present a vision for a package of improved training and support for gastrostomy care, with implications for a range of different medical procedures which families are now trained to perform at home.

11.5 Recommendations for a full package of training and support for parents caring for children with gastrostomies

In this section I explain the main components of our package of training and support for parents who care for children with gastrostomies: i) acquiring the core medical knowledge, ii) hands on practice, iii) emotional preparation and support, and iv) long-term support. For each component I discuss the main recommendations and illustrate them with examples, including examples of local implementation in our region.

11.5.1 Component 1: Acquiring the core medical knowledge

Anybody learning to perform a new medical procedure must first acquire new knowledge. Parents are currently given information about gastrostomies verbally by healthcare professionals, with most also given written information booklets to read. Booklets/information on websites and verbal information from healthcare professionals are a critical foundation and starting point for many people. However, videos and images are likely to be superior and necessary for most people. Parents are likely to benefit from short videos which cover the core medical knowledge they need to learn to care for their child's gastrostomy at the different stages of their journey. The videos will complement any verbal information given by clinicians, and any written booklets/information on websites. Figure 11.1 illustrates when in a parent's journey specific topics will be most helpful. The videos and written information are best accessed at multiple different time

points so that learning is spaced out, with information accessible from when the child is referred for a gastrostomy long before the surgery takes place.

As well as videos and written information, parents need the opportunity to ask questions to clinicians and other parents. Parents value the credibility of specialist professionals but also the lived experience and expertise of experienced parents. Families may benefit from the opportunity to participate in group videos calls with a community nurse or specialist hospital nurse soon after the child's surgery, and potentially also before the surgery. This would provide an opportunity for families to ask questions, and learn both from healthcare professionals and other families.

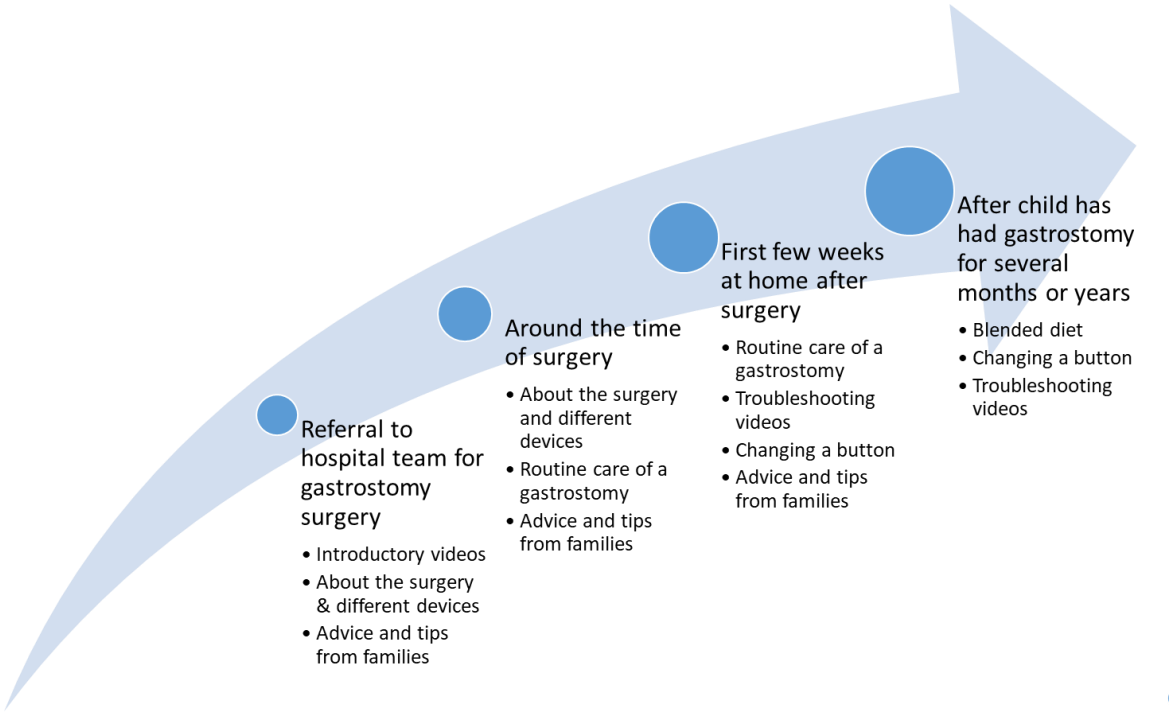


Figure 11.1 Diagram illustrating how different video topics fit within the patient pathway

11.5.2 Component 2: Hands-on practice

Developing the motor skills to perform medical procedures competently and with confidence is a vital part of a training package. At present families receive varying amounts of supervised practice on their child from nurses in hospital and the community.

This one-to-one time with a nurse observing the parent practicing on their child is clearly critical. However, many parents need more hands-on practice than they currently receive. The first hands-on-practice parents usually get is when they are asked to perform procedures on their child under supervision after the surgery: parents often feel anxious and worried about hurting their child at this point in time. It is often not possible to repeatedly practice a specific subtask of a medical skill (e.g. changing a gastrostomy button) on a child: the task may be distressing for the child or only needs to be done rarely or in emergencies. For gastrostomy care, there is often limited time in hospital after the surgery to practice core skills before the child is discharged. Simulation training (typically using mannequins or dolls) offers opportunities for deliberate practice which do not require practicing on the patient (Motola et al., 2013). In cases of procedures performed rarely (e.g. changing a gastrostomy button), simulation can allow you to develop the motor skills to perform the procedures safely in real life. It is vital that simulation practice is offered to families to help them become familiar with simple tasks before performing them on their child. At present, simulation is not routinely used with families.

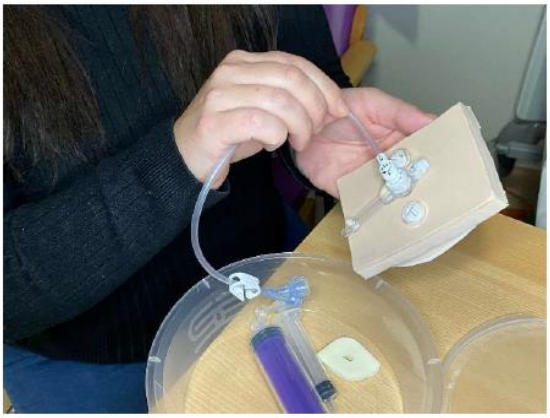
Simulation practice need not require mechanically complex equipment, but can often be done with simple equipment. Part-task trainers are used regularly for training surgeons (Walsh et al., 2018), and could be useful for training parents, e.g. part-task trainers for learning to change a gastrostomy button or connect an extension tube to a button. For example, as part of the additional funding I received from the Health Foundation to support our work developing the videos, we had some 3D-printed models designed and made for families to practice with as part of their training in hospital to care for their child's gastrostomy. The surgical team at the John Radcliffe hospital have started using

the models with families. Figure 11.2 shows the box of equipment, and a mother practicing connecting the extension tube to the button while in hospital for her child's surgery. Some quotes from parents who used the models are given below:

"The box has been extremely helpful. It's a great idea and it's so much easier to become familiar with things knowing there's no risk of hurting your child while practicing on them."

"The real advantage of the model for me and my wife came after the operation when my son was healing and we were being shown how to use the 'button' to feed him. We did things to the device that we were not prepared to do with my son's 'button' yet. The model reduced our anxiety and most importantly allowed us to get better accustomed to the procedures we are required to do with the 'button' more quickly."

Box of equipment given to parents so they can get hands on practice before doing the procedures on their children



A mother practicing connecting the extension tube to the gastrostomy button while in hospital for child's surgery

Figure 11.2 Photos showing the box of equipment designed for simulation practice and a parent practising at the John Radcliffe

From piloting the gastrostomy equipment with parents, we know parents appreciate the opportunity to get hands-on practice without worrying about hurting their child. Simulation practice is a core part of our training package, both because of its benefits for

skill development and the emotional benefits for families of practicing without the risk of hurting their child.

11.5.3 Component 3: Emotional preparation and support

It is critical that training and support addresses the emotional impact of the whole family. Currently families may receive some emotional support through conversations with clinicians and through peer support (through friends, Facebook support groups and charities). A support package needs to include a range of resources for parents explicitly addressing their emotional needs. This section explores some key areas where support is needed.

11.5.3.1 Addressing the emotional impact on parents

Firstly we must address the emotional impact on parents at the start of their journey. For example, the impact on parents of not being able to feed their child "normally", and eat meals together, is one critical issue. This should be acknowledged in training and support resources (including in videos), and in consultations with clinicians. There is an excellent video discussing the emotional impact of tube feeding on families produced in Scotland: https://www.cen.scot.nhs.uk/educational-resources-dvds/ . In our library of videos we have addressed some of these issues (see Box 11.1 for relevant quotes from the videos). There are also some useful resources recently produced by a group of families, researchers and clinicians in Sydney, with families describing their journeys: https://childfeeding.org/real-stories/. Clinicians should discuss these issues with families when supporting them with the decision to have a gastrostomy device inserted. Families will benefit from hearing the stories of other families (either through videos or meeting other families). Clinicians should also signpost families to resources for peer support, including Facebook support groups and charities, and provide opportunities for parents

Box 11.1: Quotes from the library of videos addressing the emotional impact

Video Title: 'Advice and tips from an experienced parent'

"I remember when Sam got his PEG for the first time. I remember putting away all the materials that he was no longer going to use because he wasn't going to be feeding and I remember the heartbreak. I remember the first time we sat around the table with the highchair seemed really pointless…. But guess what, it works out, it becomes normal, it becomes part of family life. It becomes part of your kitchen, your daily routine and it's all ok."

Watch the full video: https://www.youtube.com/watch?v=NhSNrRdKcO0

Video Title: 'Advice from a new a family'

"And although it was a big emotional decision, and a big thing for us to do, ultimately it was the right things for us to do and it saved our daughter's life. So swapping the mindset to having meals at the table with a knife and fork and cutlery, to then having this button is a really big thing and it's a big journey for any parent to go on."

"*There's an amazing Facebook group for tube feeding your child and I joined that really early on and on there, there are other parents living and breathing exactly what you are going through at that moment in time. People who are about to get their operation, people who have had children on tubes since they were born and using them as a support network is fantastic and that has really helped us."*

"In order to prepare my daughter for surgery, we started going down the story route and decided to call it our fairy door because she's really into fairies and the hospital staff said it was a really nice way of introducing this magic door going into her tummy."

Watch the full video: https://www.youtube.com/watch?v=bJid9clg0Hs

to meet other families going through a similar journey to them. When parents are learning to care for their child's gastrostomy, resources (e.g. videos and information on websites) need to address common worries, for example, worries about what to do if the

gastrostomy button comes out or worries about hurting the stoma site. Clinicians also need to provide time and space to discuss parents' worries with them.

Later in their journey, when a parent is learning to change a gastrostomy button, it is important to be aware that the procedure is distressing for some children and parents. Parents should be given advice on how to manage their child's distress and pain. For example in the parent information booklets on gastrostomy care used in our region, we have incorporated a list of tips for parents from other parents on emotional support, and a list of evidence-based strategies for helping a child manage distress before and during the procedure (https://www.patientsafetyoxford.org/clinical-safety-programmes/previous-programmes/paediatric-gastrostomy/overview/paediatric-gastrostomy-resources/booklets-for-parents/). The information on managing your child's distress is based on The British Psychological Society guidelines in 2010 on managing distressing procedures in children (The British Psychological Society, 2010). In our video on 'Changing a gastrostomy button' we incorporated advice and tips from parents from the survey in Chapter 6 on managing their child's distress (see Figure 11.3)

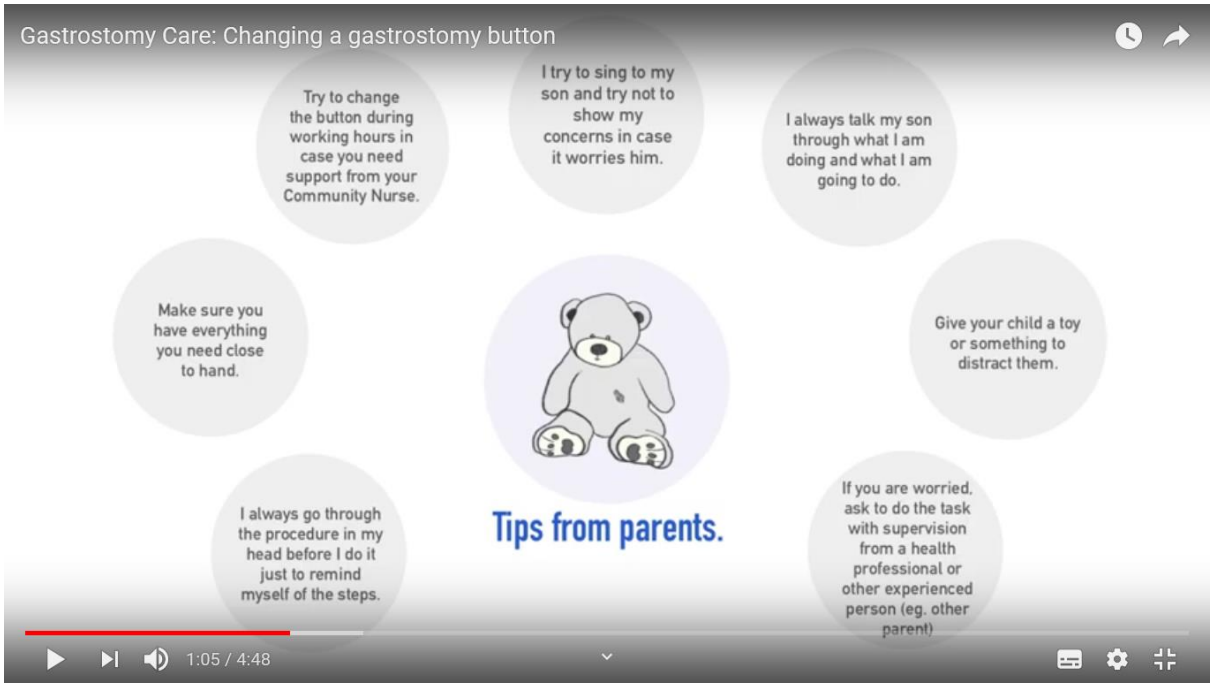


Figure 11.3 Tips from parents on managing your child's distress, as featured in the video on 'Changing a gastrostomy button'

11.5.3.2 Supporting the child

Depending on the child's age, parents may also need support explaining what a gastrostomy is to their child, and potentially also siblings and friends. It may be helpful for children to have a doll or teddy fitted with a gastrostomy for the child to play with. There are various places online which sell dolls or teddies with gastrostomies, and other medical devices (e.g. Etsy). Another helpful resources is books and online resources for

Box 11.2 List of books and online resources for explaining gastrostomies to children

- A guide for children who need a gastrostomy: https://www.gkcct.org/article/new-booklets-children
- Picture book on tube feeding for children: https://www.theabilitiesinme.com/products/tube-feeding
- The Billy Bear Button Gastrostomy story and Cameron Camel Pump story and other activities: http://www.tube-feeding.com/Downloadable-Resources/

children: Box 11.2 lists a few existing resources which are listed on the OxSTaR website alongside the library of videos (https://www.oxstar.ox.ac.uk/more/supporting-parents/resources-for-parents-and-children). Our stakeholder group have purchased some of these dolls and books for community services in our region.

11.5.4 Component 4: Long-term support

Parents need access to support and further training long-term. Currently most training is focused on the hospital admission and the first few weeks at home after surgery, with very limited, if any long-term follow-up. Parents can contact their community teams or hospital if they experience problems, but are largely left alone to manage. Many families use Facebook support groups to access information from other parents, for example when they experience problems with over-granulation at the stoma site or a blocked tube. Training needs to prepare parents for managing complications and potential problems, and also provide opportunities for parents to refresh their knowledge: evidence in the literature suggests that there are gaps in the knowledge of parents who have been caring for a child with a gastrostomy for a number of years (Evans et al., 2012, 2010), and this is also anecdotally supported by the stakeholder group supporting my work.

Parents should be able to access videos specifically targeting complications or problems parents might experience at home, available to re-watch as needed. For example our video library includes a talk from the specialist nurse at the JR hospital on treating over-granulation, a demonstration of venting (releasing trapped wind) from a children's nurse, and a talk on what to do if the button comes out by a CCN and a parent. There are also

some videos from a parent on changing a button which is a skill some parents learn to do a few months or years after their child's surgery, and a talk by a nurse and parent on blended diet (food that is blended and given through the tube, rather than prescribed feeds). The benefits of videos is that parents are able to access information when problems arise and re-watch them whenever they need.

Moderated Facebook support groups can also provide a form of long-term support. Whilst the information on these groups is not always accurate, much of the advice from experienced parents is often very good. Parents ought to be directed to relevant Facebook groups such as 'Tube Feeding your child in the UK- support group', with the caveats that the information is not always accurate, and should be checked with a healthcare professional. The moderators of these groups have a critical role in quality assurance of the information on these groups, and should have access to reliable information, e.g. our library of videos, to signpost families to.

Parents also need access to training materials for refreshing their knowledge. The videos partly assist with this, but parents should also have access to short tests to refresh their knowledge. For example, on the OxSTaR website we have created a short test which directs parents to specific videos if they are unsure of the answer (https://www.oxstar.ox.ac.uk/more/supporting-parents/check-you-knowledge). Community or hospital teams should also be responsible for sending updates of best practice out to parents. Whilst healthcare professionals have regular CPD and training updates, this is currently not provided to families.

11.6 Final reflections

This chapter has laid out the key implications from across my thesis on what a full package of training and support ought to look like for parents caring for children with gastrostomies. The content of the training and support package has been developed through discussions with the stakeholder group supporting my research over the past four years. As a group, we have been able to implement some of these recommendations into services across our region. We have designed the package around the needs of parents, both in the short and long-term, rather than starting from the point of view of a hospital or community team who support parents at specific points in their journey. There needs to be a joined up approach to training from community and hospital services. The training package needs to be delivered by a multidisciplinary team of healthcare professionals recognising their different types of expertise, and the different kinds of support they can offer families. The recommendations laid out in the chapter recognise the expertise of parents, moving away from a paternalistic model of healthcare. The training and support package described is unique in that it is really designed for and with families, supporting them practically and emotionally throughout their journey. The underlying principles of the package are also relevant to a range of other medical procedures that families now perform at home.

Chapter 12 Final discussion and conclusions

Complex medical procedures are no longer just carried out in hospitals by healthcare professionals. There are increasing numbers of families who perform complex medical procedures at home (Ten Haken et al., 2018). This thesis has focused on an example of this wider phenomena: the care provided by parents to children with complex medical needs. I have focused particularly on gastrostomy care, with references to other specialist procedures such as long-term ventilation. Families need to be provided with high-quality training and support for the responsibilities they take on, and this is not currently given the consideration it deserves. My thesis has explored what is needed in a package of training and support for families caring for children with gastrostomies, informed by the experiences of families and findings from psychology and clinical practice. This final chapter provides:

i) A summary of the findings of the thesis

ii) A discussion of the key methodological issues

iii) Future research and development

iv) Implementation of the training package into clinical practice

v) Wider clinical and policy implications

vi) Final reflections

12.1 A summary of the findings of the thesis

12.1.1 Understanding the clinical issues

In Chapters 3 and 4 I explored the concerns of healthcare professionals who support children in the community with feeding tubes and long-term ventilation, through an analysis of routine data (incident report data). Examining incident report data is a common method in health services research to investigate problems and vulnerabilities

across the healthcare system from the perspective of clinicians (Carson-Stevens, 2017; Vincent, 2004; Williams et al., 2017). The data highlighted training and support for families as a major weakness in the system: children can and do come to harm through inadequate training for parents and other carers. In order to better understand the challenges parents experience, I conducted a thematic analysis of interviews with parents who perform a range of specialist medical procedures for their children (Chapter 5). This analysis provided a rich description of the challenges families are facing and the responsibilities they hold. Parents' descriptions of managing medical procedures and emergencies highlighted the need for more preparation and support, particularly in the first few weeks and months following discharge from hospital. Together these chapters demonstrate a clear need for improving training and support for these families, and highlight some of the consequences of inadequate training and support.

In Chapter 6 I conducted two surveys with family carers to understand their experiences of training and support, and their views on how this could be improved. I found substantial variability in participants' descriptions of the training and support they received. Two in five participants rated their confidence caring for their child's gastrostomy as very low in the first few weeks after surgery. Instructional videos and simulation practice were rated as useful, in addition to face-to-face practice with a healthcare professional. Parents recommended that instructional videos should feature families as well as healthcare professionals. Troubleshooting and advice and tips from families were rated as important topics to cover, in addition to routine care. This chapter provides recommendations directly from parents for how training and support could be improved.

12.1.2 Experimental studies on enhancing training for parents

In the next section of my thesis I conducted a series of experiments to explore how we might improve the information-giving stage of training for gastrostomy care, informed by studies from the Psychology literature on optimising learning (which are described in more detail in Chapter 2). In the first two experiments I explored whether retrieval practice and schema-enhanced study materials could benefit the learning of information on gastrostomy care. Unexpectedly retrieval practice did not improve memory for the information studied when compared to re-reading the information. The schema-enhanced training was rated as significantly more understandable but actually resulted in worse performance in the test, perhaps because the (over)confidence induced led to limited effort given the opportunity to re-study. In the second experiment I found weak evidence of a small benefit of retrieval-enhanced training on learning, but not of the magnitude of the large effect sizes reported in experimental studies in the literature. Small effects will not be clinically meaningful. In the third experiment, I used a similar experimental design to investigate whether the addition of instructional videos could enhance learning and memory. I found large effects for the addition of videos and images to written information. The video-enhanced training was also rated as more understandable than studying the written information alone with or without additional images. Together these experiments suggest resources are better invested in enhancing training materials with videos and images, rather than focusing on implementing more testing into training. Another key implication from the experiments is that training materials that are rated as more understandable at the time of study can actually lead to worse learning and memory in a subsequent test (as was the case for schema-enhanced training).

12.1.3 Strategies for improving training and support for parents in the real-world

The main practical output from my thesis is a library of videos to support parents caring for a child with a gastrostomy. These videos were developed with parent representatives, nurses and paediatricians from hospital and community services, and are now used routinely with parents of children who have gastrostomy surgery at the John Radcliffe hospital. The library of videos includes the videos tested in Chapter 9 on routine care, videos on troubleshooting problems and videos featuring parents sharing their experiences and top tips, and a few videos about the surgery and other topics the stakeholder group supporting my research agreed would be important. In Chapter 10 I evaluated the videos with a sample of healthcare professionals and family carers of children with gastrostomies: the videos were found to be acceptable and valuable to both groups. The evaluation also informed how to make best use of the videos in practice. In Chapter 11 I discussed the implications for clinical practice from across my thesis, describing in detail what a full package of training and support for parents ought to look like. Chapter 11 sets out recommendations for clinicians who train parents, and also describes the practical steps we have taken across the Thames Valley region to implement some of this into practice.

12.2 Key methodological issues

I have used a broad range of methods in my thesis, from experimental studies to qualitative analysis of primary and secondary data. Individual chapters have summarised some of the strengths and limitations of different data sources and study designs. This section describes some of the core methodological issues and themes from across my thesis: the use of experiments for evaluating potential training interventions, issues of

measurement, the generalisability of experimental findings and the challenges of applying psychological theory to real-world problems.

12.2.1 Use of experiments for evaluating potential training interventions

The experiments allowed me to test potential training interventions with larger sample sizes than would be possible in the real-world context, and to control for factors that we could not control for in the real-world. It is exceedingly difficult to evaluate training interventions with parents in the real-world setting, and certainly within the time and resources constraints of a DPhil, and a global pandemic. Online experiments provided a way of exploring possible interventions in a controlled environment, before deciding what type of intervention might be worth testing in the applied setting. There are papers in the medical literature evaluating training interventions in the real world with families, but the evaluation of the effectiveness of these interventions is often limited by small sample sizes, or reliance on measures such as patient satisfaction (Boroughs, 2017; L. Kirk et al., 2014). Reliance on patient satisfaction measures may be problematic: as shown in the first experiment in my thesis (Chapter 7), training which is rated as more understandable (i.e. the schema-enhanced training) can led to worse learning and memory. It is easy to generate recommendations for what might work, but it is much more difficult to test and rigorously evaluate the effectiveness of these interventions. Using experiments to decide which interventions to invest more time and resource in and evaluate in the real-world is a method I would recommend to be used more widely.

12.2.2 Measurement

There are no validated measures of performance for assessing gastrostomy knowledge or the skills to care for a child with a gastrostomy. The simple measure of proportion correct on a delayed recognition memory test and associated confidence ratings are sensitive

measures and easy to score. I have managed to show effects of different types of interventions on these straightforward measures which are widely-used in psychology experiments. One of the challenges of evaluating training interventions is to identify what to measure.

The measures used in the experiments in my thesis are proxy measures of the real-world phenomena of interest, e.g. proportion correct on a multiple-choice test is a proxy measure for the ability to correctly perform a medical procedure on a child at home. However it is difficult to know how good they are as proxy measures for the real world outcomes of interest. In the three experiments I explored some alternative measures intended to capture something closer to procedural knowledge, e.g. coding scenario questions where participants were asked what they would do in various real-life scenarios, and putting instructions in the correct order. However, I was not able to come to any clear conclusions about which measures would be most suitable. One alternative measure that ought to be explored is observer-rated performance of procedures on a manikin or doll, which would obviously require in-person experiments rather than online experiments as utilised in my thesis.

12.2.3 Generalisability of findings from experiments

There are some obvious challenges to the generalisability of the experimental findings: for example, parents are likely to be more motivated learners and more stressed and tired that the general public who completed the online experiments which may impact on the learning process. To help mitigate against concerns relating to motivation, participants in the experiments were of parent age and were incentivised to study the materials carefully by the offer of a bonus payment for good performance in the test. Some participants with low motivation were also screened out via the minimum reading

times and attention checks. To explore issues around the effects of stress on learning, the experiments could be replicated with other types of family carers who may experience similar levels of stress (e.g. carers of children with epilepsy or severe asthma), or participants who scored above a specific cut-off point on a measure of stress, such as the Global Measure of Perceived Stress (Cohen, Kamarck, & Mermelstein, 1983). It would be helpful to first assess baseline levels of stress in parents of children awaiting gastrostomy surgery so we could quantify typical stress levels in this group. Another consideration for the generalisability of the findings relates to study time. In the experiments I purposely did not control participants' study time (allowing participants to study the information as long as they wanted) which led to large individual differences in study time. This in part reflects how we would expect people to study information in real-life contexts outside the lab, but it does not fully reflect the variability in study time and spaced-out study which would likely occur with parents learning to care for a child's gastrostomy. There are some clear challenges to the generalisability of the findings in the experiments. Although I have been able to partly address some of these concerns through choices made in the study design, further studies would be needed to address some of the concerns.

12.2.4 The challenges of applying psychological theory to applied contexts

In my thesis I have sought to apply findings from the psychology literature to the real-world problem of training parents to perform medical procedures. There is a plethora of review articles making recommendations for solving specific real-world problems based on large bodies of psychological literature, for example, a recent paper explored how social and behavioural science can support the Covid-19 response (Bavel et al., 2020) and papers have targeted teachers and policymakers suggesting how to improve learning (Regehr & Norman, 1996; Roediger & Pyc, 2012; Weidman & Baker, 2015; Weinstein et

al., 2018). To solve a real-world problem, recommendations from experiments are rarely sufficient: we need to develop and test interventions in the real-world. It may be that the recommendations from the literature do not have the intended results, or that the effects are much smaller than anticipated in the applied setting, as I found in some of my experiments. Equally there is a danger of simply applying interventions across healthcare that people think will be helpful; it may be that they do not help and waste resources, or worse that they lead to unintended harm (e.g. the schema-enhanced training led to worst performance).

In Chapter 2 I discussed a range of strategies from psychology experiments on encoding information and developing procedural knowledge that could potentially improve training for parents who are learning to perform medical procedures. It can be difficult to know which strategies are likely to be most beneficial; you cannot simply compare effect sizes since effect sizes seen in carefully-controlled lab studies may not generalise to certain real-world contexts (Dunlosky, Bottiroli, & Hartwig, 2009; Goroff, Lewis, Scheel, Scherer, & Tucker, 2018) and there may be boundary conditions to effects that limit the effectiveness of transfer (Rowland, 2014; Simons, Shoda, & Lindsay, 2017; Weinstein et al., 2018). I have not been able to test all the strategies discussed in Chapter 2 in my thesis. The empirical evidence I do have suggests large benefits for dual-coding theory, and limited benefits of retrieval practice, and potentially a detrimental impact of schema-enhanced written materials. Further research is needed to test the impact of spacing out learning in the context of training parents to care for a child's gastrostomy, and to quantify the potential benefits of deliberate practice on learning in this context. Effect sizes may be large (as was the case for adding videos and images to patient information

booklets), or effects may actually be much smaller than the literature suggests (as was the case for retrieval practice in the experiments in my thesis).

12.3 Future research and development

This section sets out some of the key area where further research and development is needed. One key area is evaluating clinical outcomes of the training package in the real-world. The section finishes with a summary of progress on local implementation of the training package and next steps for ensuring wider implementation and sustainability.

12.3.1 Developing and evaluating simulation training

Further research is needed to evaluate the impact of simulation training with parents. Simulation is a critical part of the proposed training package described in Chapter 11 but has not been formally studied in my thesis. Initial surveys were conducted with a small sample of parents at the John Radcliffe hospital who used the 3D-printed models we designed as part of their training to care for their child's gastrostomy: these brief surveys provided some initial positive feedback from a small sample of families, but we do not have a large enough sample to evaluate outcomes. Future research should look at the impact of simulation training on parental confidence, as well as performance outcomes such as the ability to perform procedures on their children. To ensure an adequate sample size, an initial study could be conducted with normal participants (rather than parents awaiting gastrostomy surgery), as was done in the experiments in my thesis. There is also an emerging literature on virtual and augmented reality training for training clinicians which is an avenue to be explored for family carers (Herron, 2016; Ruthenbeck & Reynolds, 2015). There are a small but growing number of "home-style" simulation suites for training parents and paid carers who care for children with medical complexity in the United Kingdom (e.g. https://www.wellchild.org.uk/supporting-you/wellchild-

better-home-suite/). Simulation is not currently widely used for training parents, like it is now with healthcare professionals, which is a missed opportunity and deserves further study.

12.3.2 Evaluating outcomes of the wider package of training and support

Evaluation of real-world outcomes of interest for the wider training and support package (as described in Chapter 11) is a critical next step. In order to evaluate outcomes for families and health services, a cluster-randomised trial with multiple hospitals would be needed. However as we saw in the experiments in my thesis, between-participant studies require large samples to measure even pretty big effects on simple-to-use measures (such as proportion correct on a recognition memory test). Changes in likelihoods of rare events would be very tricky to detect without very large sample sizes. Careful consideration is needed on which outcomes for parents, children and health services might be meaningful, and for which there might be a realistic prospect of detecting an effect. A clear practical constraint is how many hospitals and families could realistically be recruited. At the JR, there are around 80 children who have surgery for a gastrostomy in a typical year.

One potentially useful framework for exploring possible outcome measures further is the Kirkpatrick framework which is widely used for evaluating the results of training and learning programmes in medical education and other disciplines (Kirkpatrick, Craig, & Bittel, 1967): the framework defines four levels of evaluation: i) reactions (how participants reacted to the training), ii) learning (increases in knowledge, skills etc.), iii) behaviour (the transfer of learning to change behaviour) and iv) results (impact on the

organisation). The data in Chapter 10 has provided some useful data on reactions. Chapter 9 (the video experiment) has provided some data on learning.

Learning might be further captured by asking families a few months after their child's surgery to complete a test of knowledge, with one group randomised to watch the videos or receive the full package of training and support, and another receiving training-as-usual. Capturing procedural knowledge could involve a hands-on task as an outcome measure (rather than a test of memory). This might involve rating videos of participants performing procedures on a plastic doll or their child. A list of criteria could be developed and performance scored against these criteria.

Behaviour refers to the transfer of learning: suitable measures of behaviour might include observations of practice by parents, or any changes in the frequency of callouts to community teams for questions. Another potential outcome measure is instances of broken equipment: in Chapters 3 and 4 I found a large number of reports for broken equipment which in part may be a result of poor training.

Measures to capture results might include a reduction in rates of complications or visits to A&E or admissions to hospital. Other potentially more sensitive measures include the amount of face-to-face time parents require from healthcare professionals to train them (following watching the videos or practicing with equipment), or fewer delayed discharges after surgery: parents not feeling confident to care for their child's gastrostomy is a common reason for delayed discharges from hospital (Dekonenko et al., 2020).

12.3.3 Economic analysis

Another related avenue to explore is the economic benefits of improved training: improving training and support for families may actually save the health service money overall. For example, readmissions to hospital or prolonged hospital stays for the surgery can be costly with a night in hospital typically costing around £200-250 a day[1]. Reducing the length of stay in hospital for gastrostomy surgery is likely to be only possible with more training for parents before the surgery (Dekonenko et al., 2020). Improved training for parents could also lead to fewer instances of broken equipment: a damaged gastrostomy button for example costs around £120-150 to replace[4]. There are also potential cost savings through reduced callouts to community teams for advice and assistance.

12.4 Implementation of the training package into clinical practice

This section describes the next steps needed to support implementation of the training package and the next section discusses wider implications for policy and clinical practice.

12.4.1 Local implementation and sustainability

The library of videos are now used routinely with families of children who have gastrostomy surgery at the JR. To support implementation further, a next useful step would be to create an implementation guide for other organisations and regions interested in using the library of videos based on the findings from Chapter 10. Together with the stakeholder group, I have planned an online launch for the library of videos to help publicise them widely and assist with implementation. In order to ensure sustainability of the project, the surgical team at the hospital will be able to add or edit the videos and resources in the future working with OxSTaR training centre. Of course

[4] Costs estimated through personal contact with paediatric surgeon

much more work is needed to enable implementation more widely outside our region. Accreditation of the training materials by trusted national bodies would be an important step to enable widespread usage.

12.4.2 Differences in practice

One potential barrier to implementing the videos into practice which needs further exploration, is differences in practice across the country. In creating and evaluating the gastrostomy videos we have discovered there is huge variability in the different advice families are given, even within a region, and certainly nationally. Agreeing the content of the videos with the various healthcare professionals, organisation and families involved was challenging: it is very difficult to get agreement on what is “best practice”. One of the potential benefits of videos where the content has been verified by key professionals is that the videos themselves may help to standardise information.

12.4.3 Use of the videos for staff training

The library of videos may also be usual for staff training. In the survey with healthcare professionals in the Chapter 10, nearly all participants reflected on how the videos might be used for training staff groups as well as families. Various clinical teams have started using the videos for staff training in our region. There is often more of a drive to improve training for anybody ‘paid’ by the health and care system rather than family carers, who actually provide the majority of care for these children.

12.5 Wider clinical and policy implications

12.5.1 Key implications for clinical practice for training parents

There are a number of clear implications from my thesis for clinical practice, which have been extensively discussed in Chapter 11 which sets out recommendations for a full package of training and support for families. The main implications are summarised in

Box 12.1. What is unique about our package of training and support is that it is designed around the needs of families, supporting them from referral for a gastrostomy to long-term support at home. Families must be supported throughout their journey, both practically and emotionally. Training and support for parents is the responsibility of multiple different organisations and professionals, including hospital nurses, community nurses, surgeons, paediatricians and allied healthcare professionals such as dieticians. Training and support needs to be viewed as a system-wide responsibility.

12.5.2 Wider implications for medical and nursing education

The shift towards family-provided care at home means that healthcare organisations need to become effective health educators. The field of medical education has grown hugely, but yet little time and money has been put into training families who are performing many of the same procedures healthcare professionals are trained to do. Training and support for family carers who perform medical procedures needs investment in time and money, and also needs to be looked at from a system perspective, with a joined-up approach to training between community and hospital services. Resources should be put into developing videos with healthcare professionals and families and for developing other types of training such as simulation training which has been widely explored in the last decade for educating healthcare professionals. Medical education centres could be set up to specialise in training families; these centres could support and coach individual teams to improve the training they provide for specific types of care, to bring together key professionals from across the system (from hospital and community services) and to co-design family-centred resources such as videos and websites.

Box 12.1: Summary of key clinical implications

- Many family carers report feeling anxious and isolated without adequate training and support.
- The training that family carers report receiving to care for their child's gastrostomy varies considerably and often does not fully meet their needs.
- Training and support needs to address the emotional needs of families (such as parents' worries and the impact of not being able to feed your child normally), as well the technical aspects of the procedures they need to learn. Training must also prepare parents for troubleshooting problems, as well as routine care.
- Instructional videos and adding images to written information can benefit parents' learning.
- Parents want instructional videos to feature both healthcare professionals and parents and some of the videos to be filmed at home (rather than in hospital).
- There is a danger that training which is rated as more understandable might not actually help learning, or could even lead to worse performance. We need to evaluate the outcomes of training interventions carefully and not just rely on ratings of satisfaction with training.
- Families would value more hands-on learning. For gastrostomy care, there is limited opportunity for hands on practice during the short hospital admission. Practice with dolls and equipment could be of real benefit for enabling the repeated hands-on practice known to be effective in medical education, and needs careful evaluation.

12.5.3 The role of families in design, delivery and implementation of training

Co-production needs to be at the heart of developing training for families to ensure training and support fully meets their needs, and recognises the lived experiences and expertise of families who provide this care daily. In my DPhil I found that families were happy to film themselves at home, and to collaborate with healthcare professional to

create training resources. Providing different ways of inputting into the development of training meant that we could learn from a wider range of parents: some parents were happy to complete surveys, some to feature in videos and some to attend meetings with clinicians. Families needed to be fairly rewarded for their time and expertise. Policy makers could pay families to work with clinicians to develop training resources, and even involve experienced families in delivering training and support to new families, alongside clinicians.

12.6 Final reflections

The importance of high-quality training and support for families who perform medical procedures for their loved ones will only become more critical as time goes on. Children and adults with serious chronic conditions are living longer, and more of the burden of care is placed on families. Healthcare organisations need to work with families and across community and hospital services to develop packages of training and support for families. The adequacy of training and information for parents needs to be viewed as a system issue and vital to the safety of care at home (McDonald et al., 2017). Training ought to be developed with families, and informed by evidence on how we learn best. Psychology as a field has a lot to offer, but we must test our theories and findings in real-world contexts. Psychologists need to go further than just making recommendations and work with people in the real world context to test and develop theoretically-informed interventions.

REFERENCES

Alba, J. W., & Hasher, L. (1983). Is Memory Schematic? *Psychological Bulletin*, *93*(2), 203–231. https://doi.org/10.1037/0033-2909.93.2.203

Alonso, A., van der Meij, J., Tse, D., & Genzel, L. (2020). Naïve to expert: Considering the role of previous knowledge in memory. *Brain and Neuroscience Advances*, *4*, 239821282094868. https://doi.org/10.1177/2398212820948686

Altman, L., Breen, C., Ging, J., Burrett, S., Hoffmann, T., Dickins, E., … Woolfenden, S. (2018). "Dealing with the Hospital has Become too Difficult for Us to Do Alone" – Developing an Integrated Care Program for Children with Medical Complexity (CMC). *International Journal of Integrated Care*, *18*(3), 14. https://doi.org/10.5334/ijic.3953

Altman, L., Zurynski, Y., Breen, C., Hoffmann, T., & Woolfenden, S. (2018). A qualitative study of health care providers' perceptions and experiences of working together to care for children with medical complexity (CMC). *BMC Health Services Research*, *18*(1), 70. https://doi.org/10.1186/s12913-018-2857-8

Amin, R., Parshuram, C., Kelso, J., Lim, A., Mateos, D., Mitchell, I., … Rose, L. (2017). Caregiver knowledge and skills to safely care for pediatric tracheostomy ventilation at home. *Pediatric Pulmonology*, *52*(12), 1610–1615. https://doi.org/10.1002/ppul.23842

Anderson, R., & Pearson, D. (1984). A Schema-Theoretic View of Basic Processes in Reading Comprehension. In *Handbook of Reading Research* (pp. 255–291). New York: Longman.

Arnold, J., & Diaz, M. C. G. (2016). Simulation training for primary caregivers in the neonatal intensive care unit. *Seminars in Perinatology*, *40*(7), 466–472. https://doi.org/10.1053/j.semperi.2016.08.007

Baker, G. R., Norton, P. G., Flintoft, V., Blais, R., Brown, A., Cox, J., … Tamblyn, R. (2004). The Canadian Adverse Events Study: The incidence of adverse events among hospital patients in Canada. *CMAJ*, *170*(11):1678-86. https://doi.org/10.1503/cmaj.1040498

BAPEN. (2011). *BANS: Annual BANS Report, 2011; Artificial Nutrition Support in the UK 2000-2010.* Retrieved from https://www.bapen.org.uk/pdfs/bans_reports/bans_report_11.pdf

Barsuk, J. H., Harap, R. S., Cohen, E. R., Cameron, K. A., Grady, K. L., Wilcox, J. E., … Wayne, D. B. (2019). The Effect of Judge Selection on Standard Setting Using the Mastery Angoff Method during Development of a Ventricular Assist Device Self-Care Curriculum. *Clinical Simulation in Nursing*, *27*, 39-47.e4. https://doi.org/10.1016/j.ecns.2018.10.005

Barsuk, J. H., Wilcox, J. E., Cohen, E. R., Harap, R. S., Shanklin, K. B., Grady, K. L., … Cameron, K. A. (2019). Simulation-based mastery learning improves patient and caregiver ventricular assist device self-care skills: A randomized pilot trial. *Circulation: Cardiovascular Quality and Outcomes*, *12*(10), e005794.

https://doi.org/10.1161/CIRCOUTCOMES.119.005794

Bartlett, F. C. (1932). *Remembering: A study in experimental and social psychology.* Cambridge University Press. Retrieved from https://psycnet.apa.org/record/1995-98505-000

Bavel, J. J. V., Baicker, K., Boggio, P. S., Capraro, V., Cichocka, A., Cikara, M., … Willer, R. (2020). Using social and behavioural science to support COVID-19 pandemic response. *Nature Human Behaviour*, *4*(5), 460–471. https://doi.org/10.1038/s41562-020-0884-z

Berger, R. (2015). Now I see it, now I don't: researcher's position and reflexivity in qualitative research. *Qualitative Research*, *15*(2), 219–234. https://doi.org/10.1177/1468794112468475

Berman, L., Hronek, C., Raval, M. V, Browne, M. L., Snyder, C. L., Heiss, K. F., … Rothstein, D. H. (2017). Pediatric Gastrostomy Tube Placement: Lessons Learned from High-performing Institutions through Structured Interviews. *Pediatric Quality & Safety*, *2*(2), e016. https://doi.org/10.1097/pq9.0000000000000016

Berry, J. G., Agrawal, R. K., Cohen, E., & Kuo, D. Z. (2013). *The Landscape of Medical Care for Children with Medical Complexity*. Retrieved from www.childrenshospitals.net

Bjork, R. A., Dunlosky, J., & Kornell, N. (2013). Self-regulated learning: Beliefs, techniques, and illusions. *Annual Review of Psychology*, *64*, 417–444. https://doi.org/10.1146/annurev-psych-113011-143823

Blais, R., Sears, N. A., Doran, D., Baker, G. R., Macdonald, M., Mitchell, L., & Thalès, S. (2013). Assessing adverse events among home care clients in three Canadian provinces using chart review. *BMJ Quality & Safety*, *22*(12), 989–997. https://doi.org/10.1136/bmjqs-2013-002039

Boland, K., Maher, N., O'Hanlon, C., O'Sullivan, M., Rice, N., Smyth, M., & Reynolds, J. V. (2017). Home enteral nutrition recipients: patient perspectives on training, complications and satisfaction. *Frontline Gastroenterology*, *8*(1), 79–84. https://doi.org/10.1136/flgastro-2016-100736

Boroughs, D. (2017). An Evaluation of a Continuing Education Program for Family Caregivers of Ventilator-Dependent Children with Spinal Muscular Atrophy (SMA). *Children*, *4*(5),33. https://doi.org/10.3390/children4050033

Bradshaw, G. L., & Anderson, J. R. (1982). Elaborative encoding as an explanation of levels of processing. *Journal of Verbal Learning and Verbal Behavior*, *21*(2), 165–174. https://doi.org/10.1016/S0022-5371(82)90531-X

Bransford, J. D., & Johnson, M. K. (1972). Contextual prerequisites for understanding: Some investigations of comprehension and recall. *Journal of Verbal Learning and Verbal Behavior*, *11*(6), 717–726. https://doi.org/10.1016/S0022-5371(72)80006-9

Brennan, T. A., Hiatt, H. H., Leape, L. L., Hebert, L., Localio, A. R., Lawthers, A. G., … Weiler, P. C. (1991). Incidence of adverse events and negligence in hospitalized patients: Results of the harvard medical practice study I. *New England Journal of Medicine*. *324*:370-376 https://doi.org/10.1056/NEJM199102073240604

Brookes, I. (2019). Long-term ventilation in children. *Paediatrics and Child Health (United Kingdom)*, *29*(4), 167–171. https://doi.org/10.1016/j.paed.2019.01.013

Bucholz, E. M., Toomey, S. L., & Schuster, M. A. (2019). Trends in pediatric hospitalizations and readmissions: 2010–2016. *Pediatrics*, *143*(2), e20181958. https://doi.org/10.1542/peds.2018-1958

Burdall, O. C., Howarth, L. J., Sharrard, A., & Lee, A. C. H. (2017). Paediatric enteral tube feeding. *Paediatrics and Child Health*, *27*(8), P371-377. https://doi.org/10.1016/j.paed.2017.05.001

Callans, K. M., Bleiler, C., Flanagan, J., & Carroll, D. L. (2016). The Transitional Experience of Family Caring for Their Child With a Tracheostomy. *Journal of Pediatric Nursing*, *31*(4), 397–403. https://doi.org/10.1016/J.PEDN.2016.02.002

Callender, A. A., & McDaniel, M. A. (2009). The limited benefits of rereading educational texts. *Contemporary Educational Psychology*, *34*(1), 30–41. https://doi.org/10.1016/j.cedpsych.2008.07.001

Carney, R. N., & Levin, J. R. (2002). Pictorial Illustrations Still Improve Students' Learning from Text. *Educational Psychology Review*, *14*(1), 5–26. https://doi.org/10.1023/A:1013176309260

Carson-Stevens, A. (2017). *Generating learning from patient safety incident reports from general practice*. Cardiff University.

Carson-Stevens, A., Hibbert, P., Williams, H., Evans, H. P., Cooper, A., Rees, P., … Edwards, A. (2016). Characterising the nature of primary care patient safety incident reports in the England and Wales National Reporting and Learning System: a mixed-methods agenda-setting study for general practice. *Health Services and Delivery Research*, *4*(27), 1–76. https://doi.org/10.3310/hsdr04270

Carter, B., Bray, L., Keating, P., & Wilkinson, C. (2018). Parent-Driven Campaign Videos: An Analysis of the Motivation and Affect of Videos Created by Parents of Children With Complex Healthcare Needs. *Comprehensive Child and Adolescent Nursing*, *41*(4):276-292. https://doi.org/10.1080/24694193.2017.1373160

Carter, B., Coad, J., Bray, L., Goodenough, T., Moore, A., Anderson, C., … Widdas, D. (2012). Home-Based Care for Special Healthcare Needs. *Nursing Research*, *61*(4), 260–268. https://doi.org/10.1097/nnr.0b013e31825b6848

Cass, H., Barclay, S., Gerada, C., Lumsden, D. E., & Sritharan, K. (2019). Complexity and challenge in paediatrics: A roadmap for supporting clinical staff and families. *Archives of Disease in Childhood*. https://doi.org/10.1136/archdischild-2018-315818

Cecilio-Fernandes, D., Cnossen, F., Jaarsma, D. A. D. C., & Tio, R. A. (2018). Avoiding Surgical Skill Decay: A Systematic Review on the Spacing of Training Sessions. *Journal of Surgical Education*, *75*(2), 471–480. https://doi.org/10.1016/J.JSURG.2017.08.002

Cohen, E., Berry, J. G., Camacho, X., Anderson, G., Wodchis, W., & Guttmann, A. (2012). Patterns and costs of health care use of children with medical complexity. *Pediatrics*, *130*(6). https://doi.org/10.1542/peds.2012-0175

Cohen, E., Kuo, D. Z., Agrawal, R., Berry, J. G., Bhagat, S. K. M., Simon, T. D., & Srivastava, R. (2011). Children with medical complexity: an emerging population for clinical and research initiatives. *Pediatrics*, *127*(3), 529–538. https://doi.org/10.1542/peds.2010-0910

Cohen, J. (1988). *Statistical Power Analysis for the Behavioral Sciences Second Edition*. Routledge. https://doi.org/10.4324/9780203771587

Cohen, S., Kamarck, T., & Mermelstein, R. (1983). A Global Measure of Perceived Stress. *Journal of Health and Social Behavior*, *24*(4), 385-396. https://doi.org/10.2307/2136404

Colbert, C. Y., Graham, L., West, C., White, B. A., Arroliga, A. C., Myers, J. D., … Clark, J. (2015). Teaching metacognitive skills: Helping your physician trainees in the quest to "know what they don't know." *American Journal of Medicine*, *128*(3), 318–324. https://doi.org/10.1016/j.amjmed.2014.11.001

Cooke, A., & Harris, S. (2011). A toolkit to support ventilated children and young people in children's hospices. *Children's Hospices UK.* Retrieved from https://www.google.com/url?sa=t&rct=j&q=&esrc=s&source=web&cd=&cad=rja&uact=8&ved=2ahUKEwjbrKWo_4XyAhU1TRUIHfaRDGQQFjABegQIBBAD&url=http%3A%2F%2Fchipac.uk%2Fwp-content%2Fuploads%2F2016%2F03%2Fa_toolkit_to_support_ventilated_children_and_young_people_in_childrens_hospices.pdf&usg=AOvVaw3RlFUhH68BM3CvVVaS9nuh

Cousino, M. K., & Hazen, R. A. (2013). Parenting stress among caregivers of children with chronic illness: A systematic review. *Journal of Pediatric Psychology*, *38*(8):809-28. https://doi.org/10.1093/jpepsy/jst049

Craig, P., Dieppe, P., Macintyre, S., Mitchie, S., Nazareth, I., & Petticrew, M. (2008). Developing and evaluating complex interventions: The new Medical Research Council guidance. *BMJ*, 337:979–983. https://doi.org/10.1136/bmj.a1655

Craik, F. I. M., & Lockhart, R. S. (1972). Levels of processing: A framework for memory research. *Journal of Verbal Learning and Verbal Behavior*, *11*(6), 671–684. https://doi.org/10.1016/S0022-5371(72)80001-X

Craik, F. I. M., & Watkins, M. J. (1973). The role of rehearsal in short-term memory. *Journal of Verbal Learning and Verbal Behavior*, *12*(6), 599–607. https://doi.org/10.1016/S0022-5371(73)80039-8

Crosby, J., & Duerksen, D. (2005). A retrospective survey of tube-related complications in patients receiving long-term home enteral nutrition. *Digestive Diseases and Sciences*, *50*(9), 1712-7. https://doi.org/10.1007/s10620-005-2923-z

Currie, G., & Szabo, J. (2019). 'It would be much easier if we were just quiet and disappeared': Parents silenced in the experience of caring for children with rare diseases. *Health Expectations*, *22*(6), 1251–1259. https://doi.org/10.1111/hex.12958

Dalton, J., Thomas, S., Harden, M., Eastwood, A., & Parker, G. (2018). Updated meta-review of evidence on support for carers. *Journal of Health Services Research and*

Policy, 23(3), 196-207. https://doi.org/10.1177/1355819618766559

Dekonenko, C., Svetanoff, W. J., Osuchukwu, O. O., Pierce, A. L., Orrick, B. A., Sayers, K. L., … Oyetunji, T. A. (2020). Same-day discharge for pediatric laparoscopic gastrostomy. *Journal of Pediatric Surgery*, *56*(1), 26-29. https://doi.org/10.1016/j.jpedsurg.2020.09.044

Department of Health. (2011). *NHS at Home:Community Children's Nursing Services.* Retrieved from: https://www.google.com/url?sa=t&rct=j&q=&esrc=s&source=web&cd=&cad=rja&uact=8&ved=2ahUKEwjbueWGgYbyAhWOhVwKHZPDCPYQFjAAegQIBRAD&url=https%3A%2F%2Fassets.publishing.service.gov.uk%2Fgovernment%2Fuploads%2Fsystem%2Fuploads%2Fattachment_data%2Ffile%2F215708%2Fdh_124900.pdf&usg=AOvVaw3Kx0EbaNo1AB7Cu4KuZE3c

DiFazio, R., & Vessey, J. (2011). Nonmedical Out-of-Pocket Expenses: A Hidden Cost of Hospitalization. *Journal of Pediatric Nursing*. https://doi.org/10.1016/j.pedn.2010.01.010

DIPEx. (2019). HealthTalk. Retrieved from https://healthtalk.org/

Donelan, K., Hill, C. A., Hoffman, C., Scoles, K., Feldman, P. H., Levine, C., & Gould, D. (2002). Challenged To Care: Informal Caregivers In A Changing Health System. *Health Affairs*, *21*(4), 222–231. https://doi.org/10.1377/hlthaff.21.4.222

Dunlosky, J., Bottiroli, S., & Hartwig, M. (2009). Sins committed in the name of ecological validity: A call for representative design in education science. In *The Educational Psychology Series. Handbook of metacognition in education.* (pp. 430–440). New York, NY, US: Routledge/Taylor & Francis Group.

Dunlosky, J., & Rawson, K. A. (2012). Overconfidence produces underachievement: Inaccurate self evaluations undermine students' learning and retention. *Learning and Instruction*, *22*, 271–280. https://doi.org/10.1016/j.learninstruc.2011.08.003

Dunning, D. (2011). The Dunning–Kruger Effect: On Being Ignorant of One's Own Ignorance. *Advances in Experimental Social Psychology*, *44*, 247–296. https://doi.org/10.1016/B978-0-12-385522-0.00005-6

Dunning, D., Heath, C., & Suls, J. M. (2004). Flawed self-assessment implications for health, education, and the workplace. *Psychological Science in the Public Interest, Supplement*, *5*(3), 69–106. https://doi.org/10.1111/j.1529-1006.2004.00018.x

Dybwik, K., Tollåli, T., Nielsen, E. W., & Brinchmann, B. S. (2011). Fighting the system: Families caring for ventilator-dependent children and adults with complex health care needs at home. *BMC Health Services Research*, *11*(1), 156. https://doi.org/10.1186/1472-6963-11-156

Edwards, J. D., Kun, S. S., & Keens, T. G. (2010). Outcomes and causes of death in children on home mechanical ventilation via tracheostomy: An institutional and literature review. *Journal of Pediatrics*, *157*(6), 955-959.e2. https://doi.org/10.1016/j.jpeds.2010.06.012

Elo, S., & Kyngäs, H. (2008). The qualitative content analysis process. *Journal of Advanced*

Nursing, *62*(1), 107–115. https://doi.org/10.1111/j.1365-2648.2007.04569.x

Ericsson, K. A. (2004). Deliberate practice and the acquisition and maintenance of expert performance in medicine and related domains. *Academic Medicine : Journal of the Association of American Medical Colleges*, *79*(10 Suppl), S70-81.

Ericsson, K. A. (2008). Deliberate Practice and Acquisition of Expert. *Academic Emegerncy Medicine*, *15*, 988–994. https://doi.org/10.1111/j.1553-2712.2008.00227.x

Ericsson, K. A., Krampe, R. T., & Tesch-Römer, C. (2005). The role of deliberate practice in the acquisition of expert performance. *Psychological Review*, *100*(3), 363–406. https://doi.org/10.1037/0033-295x.100.3.363

Ericsson, K. A., Krampe, R. T., Tesch-romer, C., Ashworth, C., Carey, G., Grassia, J., … Schneider, V. (1993). The Role of Deliberate Practice in the Acquisition of Expert Performance. *Psychological Review, 100*(3), 363–406. https://doi.org/10.1037/0033-295X.100.3.363

Evans, S., Holden, C., & MacDonald, A. (2006). Home enteral feeding audit 1 year post-initiation. *Journal of Human Nutrition and Dietetics*, *19*(1):27-29. https://doi.org/10.1111/j.1365-277X.2006.00662.x

Evans, S., Preston, F., Daly, A., Ashmore, C., MacDonald, A., & Holden, C. (2012). Home enteral tube feeding in children with inherited metabolic disorders: a review of long-term carer knowledge and technique. *Journal of Human Nutrition and Dietetics*, *25*(6), 520-525. https://doi.org/10.1111/j.1365-277x.2012.01274.x

Evans, S., Shelton, F., Holden, C., Daly, A., Hopkins, V., & MacDonald, A. (2010). Monitoring of home safety issues in children on enteral feeds with inherited metabolic disorders. *Archives of Disease in Childhood*, *95*(9), 668–672. https://doi.org/10.1136/adc.2008.148338

Ewbank, L., Thompson, J., & McKenna, H. (2017). NHS hospital bed numbers: past, present, future. *The King's Fund, Editor*. Retrieved from https://www.kingsfund.org.uk/publications/nhs-hospital-bed-numbers

Falkson, S., Knecht, C., Hellmers, C., & Metzing, S. (2017). The Perspective of Families With a Ventilator-Dependent Child at Home. A Literature Review. *Journal of Pediatric Nursing*, *36*:213-224. https://doi.org/10.1016/j.pedn.2017.06.021

Fields, B. E., Whitney, R. L., & Bell, J. F. (2020). Home Oxygen Therapy. *AJN The American Journal of Nursing*, *120*(11), 51-57. https://doi.org/10.1097/01.naj.0000721940.02042.99

Fleming, P., Wright, M. E., MacAuley, D., McCann, S., & Madigan, S. M. (2007). General Practitioners involvement in enteral tube feeding at home: a qualitative study. *BMC Family Practice*, *8*(29). https://doi.org/10.1186/1471-2296-8-29

Fraser, L., Gibson-Smith, D., Jarvis, S., Norman, P., & Parslow, R. (2020). *"Make Every Child Count" Estimating current and future prevalence of children and young people with life-limiting conditions in the United Kingdom*. Retrieved from: https://www.togetherforshortlives.org.uk/resource/make-every-child-count/

Fraser, L. K., Murtagh, F. E. M., Aldridge, J., Sheldon, T., Gilbody, S., & Hewitt, C. (2021). Health of mothers of children with a life-limiting condition: A comparative cohort study. *Archives of Disease in Childhood*, Published Online First: 02 March 2021, 1–7. https://doi.org/10.1136/archdischild-2020-320655

Fraser, L., Miller, M., Hain, R., Norman, P., Aldridge, J., McKinney, P. A., & Parslow, R. C. (2012). Rising national prevalence of life-limiting conditions in children in England. *Pediatrics*, *129*(4), e923-9. https://doi.org/10.1542/peds.2011-2846

Ghosh, V. E., & Gilboa, A. (2014). What is a memory schema? A historical perspective on current neuroscience literature. *Neuropsychologia*, *53*(1), 104–114. https://doi.org/10.1016/j.neuropsychologia.2013.11.010

Glasson, E. J., Forbes, D., Ravikumara, M., Nagarajan, L., Wilson, A., Jacoby, P., … Downs, J. (2020). Gastrostomy and quality of life in children with intellectual disability: A qualitative study. *Archives of Disease in Childhood*, *105*:969-974. https://doi.org/10.1136/archdischild-2020-318796

Goldin, A. B., Heiss, K. F., Hall, M., Rothstein, D. H., Minneci, P. C., Blakely, M. L., … Arca, M. J. (2016). Emergency Department Visits and Readmissions among Children after Gastrostomy Tube Placement. *Journal of Pediatrics, 174*:139-145.e2. https://doi.org/10.1016/j.jpeds.2016.03.032

Goroff, D., Lewis, N., Scheel, A., Scherer, L., & Tucker, J. (2018). *The inference engine: A grand challenge to address the context sensitivity problem in social science research*. Retrieved from https://psyarxiv.com/j8b9a

Grantcharov, T. P., & Reznick, R. K. (2008). Teaching procedural skills. *BMJ, 336*(7653), 1129–1131. https://doi.org/10.1136/bmj.39517.686956.47

Greve, A., Cooper, E., Tibon, R., Henson, R. N., Greve, A., Cooper, E., … Henson, R. N. (2018). Knowledge Is Power : Prior Knowledge Aids Memory for Both Congruent and Incongruent Events, but in Different Ways. *Journal of Experimental Psychology: General, 148*(2), 325-341. https://doi.org/10.1037/xge0000498

Hasher, L., & Alba, J. W. (1983). Is memory schematic. *Psychological Bulletin*, *93*(2), 203–231. https://doi.org/10.1037/0033-2909.93.2.203

Healey, F., Sanders, D. S., Lamont, T., Scarpello, J., & Agbabiaka, T. (2010). Early detection of complications after gastrostomy: summary of a safety report from the National Patient Safety Agency. *BMJ, 340*, c2160. https://doi.org/10.1136/bmj.c2160

Heaton, J. (2004). Reworking Qualitative Data. In *Reworking Qualitative Data* (pp. 35–52). https://doi.org/10.4135/9781849209878

Heiser Rosenberg, C. E., Terhaar, M. F., Ascenzi, J. A., Walbert, A., Kokoszka, K. M., Perretta, J. S., & Miller, M. R. (2017). Becoming Parent and Nurse: High-Fidelity Simulation in Teaching Ambulatory Central Line Infection Prevention to Parents of Children with Cancer. *Joint Commission Journal on Quality and Patient Safety*, *43*(5), 251–258. https://doi.org/10.1016/j.jcjq.2017.02.007

Hernan, A. L., Giles, S. J., Fuller, J., Johnson, J. K., Walker, C., Dunbar, J. A., & Green, G. (2015). Patient and carer identified factors which contribute to safety incidents in

primary care: a qualitative study. *BMJ Quality and Safety*, *24*(9), 585–593. https://doi.org/10.1136/bmjqs

Herron, J. (2016). Augmented Reality in Medical Education and Training. *Journal of Electronic Resources in Medical Libraries*, *13*(2), 51–55. https://doi.org/10.1080/15424065.2016.1175987

Herxheimer, A., & Ziebland, S. (2008). The DIPEx Project: Collecting Personal Experiences of Illness and Health Care. In *Narrative Research in Health and Illness*, 115–131. https://doi.org/10.1002/9780470755167.ch7

Hillis, R., Brenner, M., Larkin, P. J., Cawley, D., & Connolly, M. (2016). The role of care coordinator for children with complex care needs: A systematic review. *International Journal of Integrated Care*, *16*(2), 12. https://doi.org/10.5334/ijic.2250

Hinton, L., & Armstrong, N. (2020). 'They don't know themselves, so how can they tell us?': parents navigating uncertainty at the frontiers of neonatal surgery. *Sociology of Health and Illness*, *42*(S1), 51–68. https://doi.org/10.1111/1467-9566.13073

Hinton, L., Locock, L., Long, A.-M., & Knight, M. (2018). What can make things better for parents when babies need abdominal surgery in their first year of life? A qualitative interview study in the UK. *BMJ Open*, *8*(6), e020921. https://doi.org/10.1136/bmjopen-2017-020921

HM Government. (2008). Carers at the heart of 21st - century families and communities. *Department of Health*. Accessed from: https://www.google.com/url?sa=t&rct=j&q=&esrc=s&source=web&cd=&ved=2ahUKEwi4s_rvhobyAhXyweYKHeYtB_sQFjAAegQIBRAD&url=https%3A%2F%2Fassets.publishing.service.gov.uk%2Fgovernment%2Fuploads%2Fsystem%2Fuploads%2Fattachment_data%2Ffile%2F136492%2Fcarers_at_the_heart_of_21_century_families.pdf&usg=AOvVaw3Maz0afYUI1IJliLrHlDjt

Institute for Healthcare Improvement. (2018). *No Place Like Home: Advancing the Safety of Care in the Home*. Accessed from: http://www.ihi.org/resources/Pages/Publications/No-Place-Like-Home-Advancing-Safety-of-Care-in-the-Home.aspx

Issenberg, S. B., Mcgaghie, W. C., Petrusa, E. R., Gordon, D. L., Scalese, R. J., Issenberg, S. B., … Scalese, R. J. (2005). Features and uses of high-fidelity medical simulations that lead to effective learning : a BEME systematic review. *Medical Teacher*, *27*(1), 10–28. https://doi.org/10.1080/01421590500046924

Kang, S. H. K., McDermott, K. B., & Roediger, H. L. (2007). Test format and corrective feedback modify the effect of testing on long-term retention. *European Journal of Cognitive Psychology*, *19*(4–5), 528–558. https://doi.org/10.1080/09541440601056620

Karpicke, J. D., & Grimaldi, P. J. (2012). Retrieval-Based Learning: A Perspective for Enhancing Meaningful Learning. *Educational Psychology Review*, *24*(3), 401–418. https://doi.org/10.1007/s10648-012-9202-2

Karpicke, J. D., & Roediger, H. L. (2008). The Critical Importance of Retrieval for Learning.

Science, *319*(5865), 966–968. https://doi.org/10.1126/science.1152408

Katz, S., Selvadurai, H., Keilty, K., Mitchell, M., & MacLusky, I. (2004). Outcome of non-invasive positive pressure ventilation in paediatric neuromuscular disease. *Archives of Disease in Childhood*, *89*(2), 121–124. https://doi.org/10.1136/adc.2002.018655

Keilty, K., Cohen, E., Spalding, K., Pullenayegum, E., & Stremler, R. (2018). Sleep disturbance in family caregivers of children who depend on medical technology. *Archives of Disease in Childhood*, *103*, 137–142. https://doi.org/10.1136/archdischild-2016-312205

Kirk, L., Shelley, A., Battles, M., & Latty, C. (2014). Educating Parents on Gastrostomy Devices: Necessary Components to Achieve Success. *Journal of Pediatric Nursing*, *29*(5), 457–465. https://doi.org/10.1016/J.PEDN.2014.05.002

Kirk, S., & Glendinning, C. (2004). Developing services to support parents caring for a technology-dependent child at home. *Child: Care, Health and Development*, *30*(3), 209–218. https://doi.org/10.1111/j.1365-2214.2004.00393.x

Kirkland-Kyhn, H., Generao, S. A., Teleten, O., & Young, H. M. (2018). Teaching Wound Care to Family Caregivers. *American Journal of Nursing*, *118*(3), 63–67. https://doi.org/10.1097/01.NAJ.0000530941.11737.1c

Kirkpatrick, D., Craig, R., & Bittel, L. (1967). *Training and development handbook.* New York: McGraw Hill.

Kish, A. M., Newcombe, P. A., & Haslam, D. M. (2018). Working and caring for a child with chronic illness: A review of current literature. *Child: Care, Health and Development*, *44*(3), 343–354. https://doi.org/10.1111/cch.12546

Kruger, J., & Dunning, D. (1999). Unskilled and unaware of it: how difficulties in recognizing one's own incompetence lead to inflated self-assessments. *Journal of Personality and Social Psychology*, *77*(6), 1121–1134. https://doi.org/10.1037//0022-3514.77.6.1121

Kun, S. S., Davidson-Ward, S. L., Hulse, L. M., & Keens, T. G. (2010). How much do primary care givers know about tracheostomy and home ventilator emergency care? *Pediatric Pulmonology*. https://doi.org/10.1002/ppul.21169

Kuo, D. Z. (2011). A National Profile of Caregiver Challenges Among More Medically Complex Children With Special Health Care Needs. *Archives of Pediatrics & Adolescent Medicine*, *165*(11), 1020. https://doi.org/10.1001/archpediatrics.2011.172

Lakens, D. (2013). Calculating and reporting effect sizes to facilitate cumulative science: A practical primer for t-tests and ANOVAs. *Frontiers in Psychology*, *4*, 863. https://doi.org/10.3389/fpsyg.2013.00863

Lawton, R., McEachan, R. R. C., Giles, S. J., Sirriyeh, R., Watt, I. S., & Wright, J. (2012). Development of an evidence-based framework of factors contributing to patient safety incidents in hospital settings: A systematic review. *BMJ Quality and Safety*, *21*, 369–380. https://doi.org/10.1136/bmjqs-2011-000443

Lee, J., & Lynn, F. (2017). Mental health and well-being of parents caring for a ventilator-dependent child. *Nursing Children and Young People*, *29*(5), 33–40. https://doi.org/10.7748/ncyp.2017.e844

Levine, C., Halper, D., Peist, A., & Gould, D. A. (2010). Bridging troubled waters: Family caregivers, transitions, and long-term care. *Health Affairs*, *29*(1), 116–124. https://doi.org/10.1377/hlthaff.2009.0520

Lloyd-Owen, S. J., Donaldson, G. C., Ambrosino, N., Escarabill, J., Farre, R., Fauroux, B., … Wedzicha, J. A. (2005). Patterns of home mechanical ventilation use in Europe: Results from the Eurovent survey. *European Respiratory Journal*, *25*(6), 1025–1031. https://doi.org/10.1183/09031936.05.00066704

Lorenc, T., & Oliver, K. (2014). Adverse effects of public health interventions: a conceptual framework. *J Epidemiol Community Health*, *68*(3), 288–290. https://doi.org/10.1136/jech-2013-203118

Lyons, I., & Blandford, A. (2018). Safer healthcare at home: Detecting, correcting and learning from incidents involving infusion devices. *Applied Ergonomics*, *67*, 104–114. https://doi.org/10.1016/j.apergo.2017.09.010

Macrae, C. (2016). The problem with incident reporting. *BMJ Quality and Safety*, *25*(2), 71–75. https://doi.org/10.1136/bmjqs-2015-004732

Maddison, J., Taylor, J., O'Neill, M., Cade, J., Hewitt, C., Horridge, K., … Beresford, B. (2021). Outcomes for gastrostomy-fed children and their parents: qualitative findings from the 'Your Tube' study. *Developmental Medicine & Child Neurology*, *Early View*. https://doi.org/10.1111/DMCN.14868

Madigan, E. A. (2007). A Description of Adverse Events in Home Healthcare. *Home Healthcare Nurse: The Journal for the Home Care and Hospice Professional*, *25*(3), 191–197. https://doi.org/10.1097/01.NHH.0000263437.08062.cc

Mair, F. S., & May, C. (2014). Thinking about the burden of treatment. *BMJ*, *349*, g6680. https://doi.org/10.1136/bmj.g6680

Maran, N. J., & Glavin, R. J. (2003). Low- to high-fidelity simulation - a continuum of medical education? *Medical Education*, *37*(Suppl 1), 22–28.

Margolan, H., Fraser, J., Lenton. S., (2004). Parental experience of services when their child requires long-term ventilation. Implications for commissioning and providing services. *Child: Care, Health and Development*, *30*(3), 257–264. https://doi.org/10.1111/j.1365-2214.2004.00414.x

Masotti, P., McColl, M. A., & Green, M. (2010). Adverse events experienced by homecare patients: A scoping review of the literature. *International Journal for Quality in Health Care*, *22*(2), 115–125. https://doi.org/10.1093/intqhc/mzq003

Massoth, C., Röder, H., Ohlenburg, H., Hessler, M., Zarbock, A., Pöpping, D. M., & Wenk, M. (2019). *High-fidelity is not superior to low-fidelity simulation but leads to overconfidence in medical students*. *BMC Medical Education,* 19(1), 29. https://doi.org/10.1186/s12909-019-1464-7

May, C., Eton, D. T., Boehmer, K., Gallacher, K., Hunt, K., MacDonald, S., … Shippee, N. (2014). Rethinking the patient: using Burden of Treatment Theory to understand the changing dynamics of illness. *BMC Health Services Research*, *14*(1), 281. https://doi.org/10.1186/1472-6963-14-281

May, C., Montori, V. M., & Mair, F. S. (2009). We need minimally disruptive medicine. *BMJ*, *339*, b2803. https://doi.org/10.1136/bmj.b2803

Mayer, R. E. (2002). Multimedia learning. *Psychology of Learning and Motivation*, *41*, 85–139. https://doi.org/10.1016/S0079-7421(02)80005-6

Mayer, R. E., Mayer, R. E., & Gallini, J. K. (1990). When is an illustration worth ten thousand words. *Journal of Educational Psychology*, *82*(4), 715–726. https://doi.org/10.1037/0022-0663.82.4.715

McCann, D., Bull, R., & Winzenberg, T. (2012). The daily patterns of time use for parents of children with complex needs: A systematic review. *Journal of Child Health Care*, *16*(1), 26–52. https://doi.org/10.1177/1367493511420186

McCann, D., Bull, R., & Winzenberg, T. (2015). Sleep Deprivation in Parents Caring for Children With Complex Needs at Home. *Journal of Family Nursing*, *21*(1), 86–118. https://doi.org/10.1177/1074840714562026

Mcdaniel, M. A., & Donnelly, C. M. (1996). Learning With Analogy and Elaborative Interrogation. *Journal of Educational Psychology*, *88*(3), 508–519. https://doi.org/10.1037/0022-0663.88.3.508

McDonald, J., McKinlay, E., Keeling, S., & Levack, W. (2015). How family carers engage with technical health procedures in the home: A grounded theory study. *BMJ Open*, *5*(e007761). https://doi.org/10.1136/bmjopen-2015-007761

McDonald, J., McKinlay, E., Keeling, S., & Levack, W. (2016). Becoming an expert carer: the process of family carers learning to manage technical health procedures at home. *Journal of Advanced Nursing*, *72*(9), 2173–2184. https://doi.org/10.1111/jan.12984

McDonald, J., McKinlay, E., Keeling, S., & Levack, W. (2017). Complex home care: challenges arising from the blurring of boundaries between family and professional care. *Kōtuitui: New Zealand Journal of Social Sciences Online*, *12*(2), 246–255. https://doi.org/10.1080/1177083X.2017.1373681

McDougall, C. M., Adderley, R. J., Wensley, D. F., & Seear, M. D. (2013). Long-term ventilation in children: longitudinal trends and outcomes. *Archives of Disease in Childhood*, *98*(9), 660–665. https://doi.org/10.1136/archdischild-2012-303062

McGaghie, W. C. (2012). Does Simulation-based Medical Education with Deliberate Practice Yield Better Results than Traditional Clinical Education? A Meta-Analytic Comparative Review of the Evidence. *Academic Medicine*, *86*(6), 706–711. https://doi.org/10.1097/ACM.0b013e318217e119.Does

Mitchell, T. K. (2020). *The impact of medical technology upon the home and feelings of at-homeness for children and young people with complex health care needs and their family members.* Tracy Karen Mitchell. Edge Hill University.

Moorman, S. M., & Macdonald, C. (2013). Medically complex home care and caregiver strain. *Gerontologist*, *53*(3), 407–417. https://doi.org/10.1093/geront/gns067

Motola, I., Devine, L. A., Chung, H. S., Sullivan, J. E., & Issenberg, S. B. (2013). Simulation in healthcare education: a best evidence practical guide. AMEE Guide No. 82. *Medical Teacher*, *35*(10), e1511-30. https://doi.org/10.3109/0142159X.2013.818632

Moulton, C.-A. E., Dubrowski, A., MacRae, H., Graham, B., Grober, E., & Reznick, R. (2006). Teaching Surgical Skills: What Kind of Practice Makes Perfect? *Annals of Surgery*, *244*(3), 400–409. https://doi.org/10.1097/01.sla.0000234808.85789.6a

Mumford, V., Baysari, M. T., Kalinin, D., Raban, M. Z., McCullagh, C., Karnon, J., & Westbrook, J. I. (2018). Measuring the financial and productivity burden of paediatric hospitalisation on the wider family network. *Journal of Paediatrics and Child Health*, *54*(9), 987–996. https://doi.org/10.1111/jpc.13923

National Research Council. (2010). *The Role of Human Factors in Home Health Care: Workshop Summary*. https://doi.org/10.17226/12927

Nelson, T. O., Dunlosky, J., Graf, A., & Narens, L. (1994). Utilization of Metacognitive Judgments in the Allocation of Study During Multitrial Learning. *Psychological Science*, *5*(4), 207–213.

NHS Improvement. (2016). *Nasogastric tube misplacement: continuing risk of death and severe harm*. Retrieved from www.england.nhs.uk/patientsafety/never-events/

NHS Improvement. (2018). Learning from patient safety incidents. Retrieved from https://webarchive.nationalarchives.gov.uk/20200501110605/https://improvement.nhs.uk/resources/learning-from-patient-safety-incidents/

Nisbett, R. E., & Wilson, T. D. (1977). Telling More Than We Can Know: Verbal Reports on Mental Processes. *Psychological Review,* 84(3), 231–259. https://doi.org/10.1037/0033-295X.84.3.231

Northington, L. D., Lyman, B., Guenter, P., Irving, S. Y., & Duesing, L. (2017). Current Practices in Home Management of Nasogastric Tube Placement in Pediatric Patients: A Survey of Parents and Homecare Providers. *Journal of Pediatric Nursing*, *33*, 46-53. https://doi.org/10.1016/j.pedn.2017.01.005

Open Science Collaboration. (2015). PSYCHOLOGY. Estimating the reproducibility of psychological science. *Science*, *349*(6251), aac4716. https://doi.org/10.1126/science.aac4716

Page, B., Nawaz, R., Haden, S., Vincent, C., & Lee, A. C. H. (2019). Paediatric enteral feeding at home: An analysis of patient safety incidents. *Archives of Disease in Childhood*, *104*, 1174–1180. https://doi.org/10.1136/archdischild-2019-317090

Paget, A., & Cadywould, C. (2015). *Life to the full: Care and support in the UK for disabled children and children with life-limiting and life-threatening conditions*. Retrieved from http://www.truecolourstrust.org.uk/wp-content/uploads/2015/11/Life-to-the-full-Main-Report.pdf

Paivio, A. (1990). *Mental representations: A dual coding approach*. Oxford University

Press.

Parand, A., Garfield, S., Vincent, C., & Franklin, B. D. (2016). Carers' Medication Administration Errors in the Domiciliary Setting: A Systematic Review. *PLOS ONE*, *11*(12), e0167204. https://doi.org/10.1371/journal.pone.0167204

Polit, D. F., & Beck, C. T. (2010). Generalization in quantitative and qualitative research: Myths and strategies. *International Journal of Nursing Studies*, *47*(11), 1451–1458. https://doi.org/10.1016/j.ijnurstu.2010.06.004

Pordes, E., Gordon, J., Sanders, L. M., & Cohen, E. (2018). Models of care delivery for children with medical complexity. *Pediatrics*, *141*(Supplement 3), S212–S223. https://doi.org/10.1542/peds.2017-1284F

Pressley, M., McDaniel, M. A., Turnure, J. E., Wood, E., & Ahmad, M. (1987). Generation and precision of elaboration: Effects on intentional and incidental learning. *Journal of Experimental Psychology: Learning, Memory, and Cognition*, *13*(2), 291–300. https://doi.org/10.1037/0278-7393.13.2.291

Puntis, J. W. L. (2009). Benefits and management of gastrostomy. *Paediatrics and Child Health*, *19*(9), 415–424. https://doi.org/10.1016/j.paed.2009.05.002

Rawson, K. A., O'Neil, R., & Dunlosky, J. (2011). Accurate Monitoring Leads to Effective Control and Greater Learning of Patient Education Materials. *Journal of Experimental Psychology: Applied*, *17*(3), 288–302. https://doi.org/10.1037/a0024749

Rawson, K. A., & Zamary, A. (2019). Why is free recall practice more effective than recognition practice for enhancing memory? Evaluating the relational processing hypothesis. *Journal of Memory and Language*, *105*, 141–152. https://doi.org/10.1016/j.jml.2019.01.002

Ray, S., Brierley, J., Bush, A., Fraser, J., Halley, G., Harrop, E. J., & Casanueva, L. (2018). Towards developing an ethical framework for decision making in long-term ventilation in children. *Archives of Disease in Childhood*, *103*(11), 1080–1084. https://doi.org/10.1136/archdischild-2018-314997

Rees, P., Edwards, A., Panesar, S., Powell, C., Carter, B., Williams, H., … Carson-Stevens, A. (2015). Safety incidents in the primary care office setting. *Pediatrics*, *135*(6), 1027–1035. https://doi.org/10.1542/peds.2014-3259

Regehr, G., & Norman, G. R. (1996). Issues in cognitive psychology: implications for professional education. *Academic Medicine, 71*(9), 988–1001. https://doi.org/10.1097/00001888-199609000-00015

Reinhard, S., Levine, C., & Samis, S. (2012). HOME ALONE: Family Caregivers Providing Complex Chronic Care. *AARP Public Policy Institute*. Retrieved from: https://www.aarp.org/ppi/info-2018/home-alone-family-caregivers-providing-complex-chronic-care.html

Roediger, H. L., & Karpicke, J. D. (2006a). Test-Enhanced Learning Taking Memory Tests Improves Long-Term Retention. *Psychological Science*, *17*(3), 249–255. https://doi.org/10.1111/j.1467-9280.2006.01693.x

Roediger, H. L., & Karpicke, J. D. (2006b). The Power of Testing Memory Basic Research and Implications for Educational Practice. *Perspectives on Psychological Science*, *1*(3), 181–210. https://doi.org/10.1111/j.1745-6916.2006.00012.x

Roediger, H. L., & Pyc, M. A. (2012). Inexpensive techniques to improve education: Applying cognitive psychology to enhance educational practice. *Journal of Applied Research in Memory and Cognition*, *1*(4), 242–248. https://doi.org/10.1016/J.JARMAC.2012.09.002

Rosen, D., Schneider, R., Bao, R., Burke, P., Ceballos, C., Hoffstadter-Thal, K., & Benkov, K. (2016). Home Nasogastric Feeds. *Journal of Parenteral and Enteral Nutrition*, *40*(3), 350–354. https://doi.org/10.1177/0148607114551967

Rowland, C. A. (2014). The effect of testing versus restudy on retention: a meta-analytic review of the testing effect. *Psychological Bulletin*, *140*(6), 1432–1463. https://doi.org/10.1037/a0037559

Ruthenbeck, G. S., & Reynolds, K. J. (2015). Virtual reality for medical training: The state-of-the-art. *Journal of Simulation*, *9*(1), 16–26. https://doi.org/10.1057/jos.2014.14

Sari, A. B.-A., Sheldon, T. A., Cracknell, A., & Turnbull, A. (2007). Sensitivity of routine system for reporting patient safety incidents in an NHS hospital: retrospective patient case note review. *BMJ*, *334*(7584), 79. https://doi.org/10.1136/BMJ.39031.507153.AE

Schalkers, I., Dedding, C. W. M., & Bunders, J. F. G. (2015). "[I would like] a place to be alone, other than the toilet" - Children's perspectives on paediatric hospital care in the Netherlands. *Health Expectations*, *18*(6), 2066–2078. https://doi.org/10.1111/hex.12174

Schubert, C. C., Wears, R. L., Holden, R. J., & Hunte, G. S. (2017). Patients as a source of resilience. In *Resilient Health Care, Volume 2* (pp. 237–254). CRC Press.

Schwieren, J., Barenberg, J., & Dutke, S. (2017). The Testing Effect in the Psychology Classroom: A Meta-Analytic Perspective. *Psychology Learning and Teaching*, *16*(2), 179–196. https://doi.org/10.1177/1475725717695149

Sears, N., Baker, G. R., Barnsley, J., & Shortt, S. (2013). The incidence o f adverse events among home care patients. *International Journal for Quality in Health Care*, *25*(1), 16–28. https://doi.org/10.1093/intqhc/mzs075

Sekhon, M., Cartwright, M., & Francis, J. J. (2017). Acceptability of healthcare interventions: An overview of reviews and development of a theoretical framework. *BMC Health Services Research*, *17*(1). https://doi.org/10.1186/s12913-017-2031-8

Silver, N. C., & Dunlap, W. P. (1987). Averaging correlation coefficients: Should Fisher's z transformation be used? *Journal of Applied Psychology, 72*(1), 146–148. https://doi.org/10.1037/0021-9010.72.1.146

Simons, D. J., Shoda, Y., & Lindsay, D. S. (2017). Constraints on Generality (COG): A Proposed Addition to All Empirical Papers. *Perspectives on Psychological Science*, *12*(6), 1123–1128. https://doi.org/10.1177/1745691617708630

Smith, C., & Scarf, D. (2017). Spacing Repetitions Over Long Timescales: A Review and a Reconsolidation Explanation. *Frontiers in Psychology*, *8*, 962. https://doi.org/10.3389/fpsyg.2017.00962

Smith, Floerke, V. A., & Thomas, A. K. (2016). Retrieval practice protects memory against acute stress. *Science*, *354*(6315), 1046–1048. https://doi.org/10.1126/science.aah5067

Sobotka, S. A., Lynch, E., Quinn, M. T., Awadalla, S. S., Agrawal, R. K., & Peek, M. E. (2019). Unmet Respite Needs of Children With Medical Technology Dependence. *Clinical Pediatrics*, *58*(11–12), 1175–1186. https://doi.org/10.1177/0009922819870251

Spiers, G., & Beresford, B. (2017). "It goes against the grain": A qualitative study of the experiences of parents' administering distressing health-care procedures for their child at home. *Health Expectations*, *20*(5), 920–928. https://doi.org/10.1111/hex.12532

Stanley, T. A., Battles, M., Bezruczko, N., & Latty, C. (2019). Efficacy of Simulation for Caregivers of Children With a Tracheostomy. *Clinical Simulation in Nursing*, *31*, 9–16. https://doi.org/10.1016/j.ecns.2019.03.005

Stoll, B. J., Hansen, N. I., Bell, E. F., Shankaran, S., Laptook, A. R., Walsh, M. C., … Shriver, E. K. (2010). Neonatal Outcomes of Extremely Preterm Infants From the NICHD Neonatal Research Network. *Pediatrics*, *126*(3), 443–456. https://doi.org/10.1542/peds.2009-2959.

Sullivan, P. B. (2014). Pros and cons of gastrostomy feeding in children with cerebral palsy. *Paediatrics and Child Health*, *24*(8), 351–354. https://doi.org/10.1016/J.PAED.2013.11.004

Taheri, M. R., Singh, H., & Duerksen, D. R. (2011). Peritonitis After Gastrostomy Tube Replacement. *Journal of Parenteral and Enteral Nutrition*, *35*(1), 56–60. https://doi.org/10.1177/0148607110376198

Ten Haken, I., Ben Allouch, S., & Van Harten, W. H. (2018). The use of advanced medical technologies at home: A systematic review of the literature. *BMC Public Health*, *18*(1), 284. https://doi.org/10.1186/s12889-018-5123-4

Terry, G., & Braun, V. (2017). Short but Often Sweet. In *Collecting Qualitative Data*. Cambridge University Press. https://doi.org/10.1017/9781107295094.003

The British Psychological Society. (2010). *Evidence-based Guidelines for the Management of Invasive and / or Distressing Procedures with Children*. Retrieved from: https://shop.bps.org.uk/good-practice-guidelines-evidence-based-guidelines-for-the-management-of-invasive-andor-distressing

The Medical Research Council. (2019). *Developing and evaluating complex interventions*. Retrieved from www.mrc.ac.uk/complexinterventionsguidance

The National Confidential Enquiry into Patient Outcome and Death. (2020). *Balancing the Pressures*. Retrieved from www.hqip.org.uk/national-programmes.

Thiede, K. W., Anderson, M. C. M., & Therriault, D. (2003). Accuracy of metacognitive

monitoring affects learning of texts. *Journal of Educational Psychology*, *95*(1), 66–73. https://doi.org/10.1037/0022-0663.95.1.66

Thomson, J., Shah, S. S., Simmons, J. M., Sauers-Ford, H. S., Brunswick, S., Hall, D., … Beck, A. F. (2016). Financial and Social Hardships in Families of Children with Medical Complexity. *The Journal of Pediatrics*, *172*, 187-193.e1. https://doi.org/10.1016/J.JPEDS.2016.01.049

Tibballs, J., Henning, R., Robertson, C. F., Massie, J., Hochmann, M., Carter, B., … Bryan, D. (2010). A home respiratory support programme for children by parents and layperson carers. *Journal of Paediatrics and Child Health*, *46*(1–2), 57–62. https://doi.org/10.1111/j.1440-1754.2009.01618.x

Tofil, N. M., Rutledge, C., Zinkan, J. L., Youngblood, A. Q., Stone, J., Peterson, D. T., … White, M. L. (2013). Ventilator caregiver education through the use of high-fidelity pediatric simulators: A pilot study. *Clinical Pediatrics*, *52*(11), 1038–1043. https://doi.org/10.1177/0009922813505901

van Gog, T., & Sweller, J. (2015). Not New, but Nearly Forgotten: the Testing Effect Decreases or even Disappears as the Complexity of Learning Materials Increases. *Educational Psychology Review*, *27*(2), 247–264. https://doi.org/10.1007/s10648-015-9310-x

van Kampen, F., de Mol, A., Korstanje, J., Groof, F. M. de, van Meurs-Asseler, L., Stas, H., … Stoelhorst, G. (2019). Early discharge of premature infants < 37 weeks gestational age with nasogastric tube feeding: the new standard of care? *European Journal of Pediatrics*, *178*(4), 497–503. https://doi.org/10.1007/s00431-018-03313-4

Van Kesteren, M. T. R., Ruiter, D. J., Ferná Ndez, G. N., & Henson, R. N. (2012). How schema and novelty augment memory formation. *Trends Neuroscience*, *35*(4), 211–219. https://doi.org/10.1016/j.tins.2012.02.001

Vincent, C., & Amalberti, R. (2016). Safety Strategies for Care in the Home. In *Safer Healthcare* (pp. 93–111). Springer. https://doi.org/10.1007/978-3-319-25559-0_8

Vincent, C. (2004). Analysis of clinical incidents: a window on the system not a search for root causes. *BMJ Quality & Safety*, *13*, 242–243. https://doi.org/10.1136/qhc.13.4.242

Vincent, C. (2007). Incident reporting and patient safety. *BMJ*, *334*(7584), 51. https://doi.org/10.1136/bmj.39071.441609.80

Vincent, C., Taylor-Adams, S., Chapman, E. J., Hewett, D., Prior, S., Strange, P., & Tizzard, A. (2000). How to investigate and analyse clinical incidents: clinical risk unit and association of litigation and risk management protocol. *BMJ*, *320*(7237), 777–781. https://doi.org/10.1136/BMJ.320.7237.777

Vincent, C., Neale, G., & Woloshynowych, M. (2001). Adverse events in British hospitals: Preliminary retrospective record review. *BMJ*, *322*, 517. https://doi.org/10.1136/bmj.322.7285.517

Wallis, C., Paton, J. Y., Beaton, S., & Jardine, E. (2011). Children on long-term ventilatory support: 10 Years of progress. *Archives of Disease in Childhood*, *96*(11), 998–1002.

https://doi.org/10.1136/adc.2010.192864

Walsh, C., Lydon, S., Byrne, D., Madden, C., Fox, S., & O'Connor, P. (2018). The 100 Most Cited Articles on Healthcare Simulation: A Bibliometric Review. *Simulation in Healthcare*, *13*(3), 211–220. https://doi.org/10.1097/SIH.0000000000000293

Weidman, J., & Baker, K. (2015). The cognitive science of learning: Concepts and strategies for the educator and learner. *Anesthesia and Analgesia*, *121*(6), 1586–1599. https://doi.org/10.1213/ANE.0000000000000890

Weinstein, Y., Madan, C. R., & Sumeracki, M. A. (2018). Teaching the science of learning. *Cognitive Research: Principles and Implications*, *3*(1), 2. https://doi.org/10.1186/s41235-017-0087-y

Well Child. (2018). #notanurse_but. Retrieved from https://www.wellchild.org.uk/supporting-you/notanurse_but/

Whiting, M. (2019). Caring for children – '24-7': The experience of WellChild Nurses and the families for whom they are providing care and support. *Journal of Child Health Care*, *23*(1), 35–44. https://doi.org/10.1177/1367493518777149

Whiting, M., Myers, J. &, Widdas, D. (2009) Community children's nursing. In: Sines, D, Saunders, M, Forbes-Burford, J (eds), *Community Health care Nursing, 4th ed*., pp. 148–171. Chichester: Blackwell Publishers Ltd.

WHO. (2010). WHO | The Conceptual Framework for the International Classification for Patient Safety (ICPS). Retrieved from World Health Organization website: http://www.who.int/patientsafety/implementation/taxonomy/ICPS-report/en/

Williams, H., Donaldson, S. L., Noble, S., Hibbert, P., Watson, R., Kenkre, J., … Carson-Stevens, A. (2019). Quality improvement priorities for safer out-of-hours palliative care: Lessons from a mixed-methods analysis of a national incident-reporting database. *Palliative Medicine*, *33*(3), 346–356. https://doi.org/10.1177/0269216318817692

Williams, H., Sheikh, A., Powell, C., Luff, D., Carson-Stevens, A., Avery, A., … Parry, G. (2017). Patient Safety Incidents Involving Sick Children in Primary Care in England and Wales: A Mixed Methods Analysis. *PLOS Medicine*, *14*(1), e1002217. https://doi.org/10.1371/journal.pmed.1002217

Wise, M. P., Hart, N., Davidson, C., Fox, R., Allen, M., Elliott, M., … Finlay, L. (2011). Home mechanical ventilation: National registries are needed to reduce variations in care and improve patient safety. *BMJ*, *342*(7801). https://doi.org/10.1136/bmj.d1687

Woodgate, R. L., Edwards, M., Ripat, J. D., Borton, B., & Rempel, G. (2015). Intense parenting: a qualitative study detailing the experiences of parenting children with complex care needs. *BMC Pediatrics*, *15*(1), 197. https://doi.org/10.1186/s12887-015-0514-5

Wooldridge, C. L., Bugg, J. M., McDaniel, M. A., & Liu, Y. (2014). The testing effect with authentic educational materials: A cautionary note. *Journal of Applied Research in Memory and Cognition*, *3*(3), 214–221. https://doi.org/10.1016/J.JARMAC.2014.07.001

Yardley, I. E., Carson-Stevens, A., & Donaldson, L. J. (2018). Serious incidents after death: content analysis of incidents reported to a national database. *Journal of the Royal Society of Medicine*, *111*(2), 57–64. https://doi.org/10.1177/0141076817744561

Yardley, I., Yardley, S., Williams, H., Carson-Stevens, A., & Donaldson, L. J. (2018). Patient safety in palliative care: A mixed-methods study of reports to a national database of serious incidents. *Palliative Medicine*, *32*(8), 1353–1362. https://doi.org/10.1177/0269216318776846

Ziebland, S., & Hunt, K. (2014). Using secondary analysis of qualitative data of patient experiences of health care to inform health services research and policy. *Journal of Health Services Research and Policy*, *19*(3), 177–182. https://doi.org/10.1177/1355819614524187

Ziebland, S., & McPherson, A. (2006). Making sense of qualitative data analysis: an introduction with illustrations from DIPEx (personal experiences of health and illness). *Medical Education*, *40*(5), 405–414. https://doi.org/10.1111/j.1365-2929.2006.02467.x

Chapter 13 Appendices

13.1 Appendix 1: Definitions for types of feeding tube and the care required (Chapter 1)

Nasogastric feeding tubes

Nasogastric (NG) feeding is where a narrow tube is inserted through the nose down into the stomach. The tube is used to give fluids, medications and liquid food directly into the stomach. Family carers give feeds and/or medications to their child through the NG tube. Some family carers also insert new tubes themselves. NG tubes can be easily pulled out, especially by babies which means that sometimes they have to be frequently replaced.

Gastrostomy feeding

Children with a gastrostomy are fed directly into their stomach. A gastrostomy is a surgical opening through the abdomen into the stomach. A feeding device is inserted into this opening. There are many types of devices that children can have including a PEG tube (Percutaneous Endoscopic Gastrostomy) and a low-profile button device such as a MINI or MIC-Key (two different brands of gastrostomy button). Family carers give feeds and/or medications, and also care for the gastrostomy site and the skin around it. Some of the devices such as buttons need be changed regularly and can also be pulled out accidently. Some family carers insert new buttons themselves. Other tasks include changing the water in the balloon if the child has a button device, managing complications relating to the stoma site such as over-granulation, infection and leakages.

Jejunostomy feeding

A jejunostomy is a surgical opening into the beginning of the small intestine (the jejunum) which is just below the stomach. Similar to a gastrostomy, a tube is inserted into the opening. The care is very similar to gastrostomy feeding, described above. Good standards of hygiene are even more essential as the tube bypasses the anti-infection mechanisms which are present in the stomach.

13.2 Appendix 2: Free text examples of incidents with coding for enteral feeding (Chapter 3)

Example 1

Patient discharged from hospital following insertion of gastrostomy tube, community children's nursing team unaware of discharge and parents not sufficiently trained in care of daily management of tube. On home visit assessment skin granuloma forming where flange too tight to skin and daily care not carried out by parents.

Care problem:

i) *Poor communication between hospital and community team at discharge*: CCN team unaware of discharge

ii) *Family carers hasn't received the appropriate training or information:* parents not sufficiently trained

iii) *Family carers hasn't received the appropriate training or information*: parents not carrying out daily management of tube

Contributory factor: None stated

Outcome: *Harm to child:* Skin damage, pain or distress relating to gastrostomy site

Example 2

Patient Mickey gastrostomy was changed to a Mini Gastrostomy by nursing staff. Dietetic team were notified of change via voicemail received [date] p.m. Patient was sent home without correct extension set to use with new low - profile gastrostomy. Patient mother phoned [date -three days later] a.m to notify team that patient has been unable to receive supplemental enteral feed since change of gastrostomy button as has not had correct extension set.
Discussion at team meeting with CCN to take on the responsibility of finalising equipment before sent out to families. Further training provided on accurate note keeping. Team administrator not to lead on equipment decisions where clinical information / knowledge is required. CCN to contact relevant professionals when equipment changes are requested to gather accurate information. Issue with note keeper not naming key professional in the CCN notes. Training issue identified.

Care problem:

i) *Required equipment, medication and feeds not supplied at discharge:* Patient sent home without correct extension set to use with new low-profile gastrostomy

Contributory factor:

i) *Staff factors*: Equipment decisions made by team administrator who doesn't have the required clinical knowledge

Outcome: *Potential harm:* Child doesn't receive supplementary feed for three days

13.3 Appendix 3: Description of the stages of analysis for coding incidents on enteral feeding (Chapter 3)

Step 1: Familiarisation	Two authors (BP and RN) first familiarised themselves with the data by reading and rereading the reports and identifying and noting relevant themes.
Step 2: Coding the first 10% of incidents	The selected incidents were imported into NVivo, version 12. two researchers (BP and RN) initially coded 10% (n=35) of the incidents independently identifying whether the incident met the inclusion criteria and if it did, identifying i) the care management problems, ii) the contributory factors and iii) any stated outcome. The coding was compared, and any discrepancies resolved through discussion with the research team. Initial agreement was over 90%. There could be up to three care management problems and up to three contributory factors per incident. Outcomes were classified into 'clearly stated harm', 'potential harm' and 'no harm'.
Step 3: Coding the remaining incidents	The remaining incidents were split equally between the two researchers with each coding another 45% (n=156) of the incidents.
Step 4: Creating and revising the frameworks	The care management problems were grouped into sub-themes and themes through an iterative process. The two authors (BP and RN) developed the framework together, informed by existing frameworks. There are multiple other frameworks which have been developed for hospital care (Vincent et al., 2000; WHO, 2010), and one which has been designed for primary care (Carson-Stevens et al., 2016). These framework could not be applied directly to the narrow topic area of enteral

	feeding at home but they were adapted for use in this study. The contributory factors were also grouped into themes using existing frameworks as a model (Carson-Stevens et al., 2016; Lawton et al., 2012; Vincent et al., 2000).
Step 5: Final checks of the coding and the frameworks.	Incidents which were unclear were verified through discussion with the research team including author AL, a paediatric surgeon and author SH, a community paediatrician. A sample of 10% of the incidents were coded independently by the third author (AL), who has significant clinical expertise in surgical enteral feeding. Agreement was 100% for the outcomes and care problems and more than 95% for the contributory factors. A fifth author (CV) carried out a final check of the frameworks.

13.4 Appendix 4: Further information about the conditions of the children in the interviews (Chapter 5)

Exomphalos

Three of the children had exomphalos, which is an abdominal wall defect where some of the intestines and other organs develop outside the abdominal cavity during the pregnancy. The corrective surgery was to return the intestines to the abdominal cavity. These children tended to have the most complex needs of the sample. Following their corrective surgery, the children had varying levels of ongoing needs. All three of the children with exomphalos needed enteral feeding tubes (of various types) and two needed some level of respiratory support (one had a tracheostomy and another needed home oxygen for emergencies).

Hirschsprung's disease

Five of the children had Hirschsprung's disease which is a rare disorder of the bowel, where the nerve cells do not develop all of the way down the bowel. The section of bowel with no nerve cells cannot relax and it can lead to a blockage. Children with Hirschsprung's need surgery to correct this, which typically happens in the first few months of life when they are strong enough for the surgery. Some children also need stomas. The children in the interviews with Hirschsprung's disease all needed bowel washouts at home for a few weeks or months before the corrective surgery, with some continuing to need them occasionally post-surgery. One child also needed anal dilations and another had a long term stoma.

Congenital diaphragmatic hernia

One child (ID24) had a congenital diaphragmatic hernia which is a defect in the diaphragm muscle, the muscle that separates the chest and abdomen. As a result, the contents of the abdomen (stomach, intestines and/or liver) grow into the chest cavity in utero which can affect the development of the lungs. This child had continuing complex needs with a tracheostomy and feeding tube (gastrostomy).

Undiagnosed conditions

Two of the children had undiagnosed problems which required abdominal surgery. One of these children (ID35) was born healthy but at 10 weeks old became unwell very quickly – experiencing convulsions and turning blue. After several days doctors and surgeons identified that her bowel was necrotising and performed emergency surgery to remove the section of infected bowel. The child was left dependent on total parenteral nutrition (TPN) through a central line. The other child (ID14), whose diagnosis remains unknown, had a stoma fitted in an emergency at a few days old but has few ongoing needs now.

13.5 Appendix 5: Descriptions of the medical procedures performed by the parents in the interviews (Chapter 5)

Enteral tube feeding (feeding through the nose, stomach or bowel)

Nasogastric feeding tubes:

Nasogastric (NG) feeding is where a narrow tube is inserted through the nose down into the stomach. The tube is used to give fluids, medications and liquid food directly into the stomach. Family carers give feeds and/or medications to their child through the NG tube. Some family carers also insert new tubes themselves. Parents need to pH test the tube (to avoid feeding in to the lungs if the tube is misplaced).

Gastrostomy feeding (e.g. PEG, button):

Children with a gastrostomy are fed directly into their stomach. A gastrostomy is a surgical opening through the abdomen into the stomach. A feeding device is inserted into this opening. There are many types of devices that children can have including a PEG tube (Percutaneous Endoscopic Gastrostomy) and a low-profile button device such as a MINI or MIC-Key. Family carers give feeds and/or medications, and also care for the gastrostomy site and the skin around it. Some of the devices such as buttons need be changed regularly and can also be pulled out by accident. Some family carers insert new buttons themselves.

Jejunostomy feeding:

A jejunostomy is a surgical opening into the beginning of the small intestine (the jejunum) which is just below the stomach. Similar to a gastrostomy, a tube is inserted into the opening. The care is very similar to gastrostomy feeding, described above. Good

standards of hygiene are even more essential as the tube bypasses the anti-infection mechanisms which are present in the stomach.

Total parenteral nutrition

In total parenteral nutrition feeds/fluids are administered directly into the bloodstream (usually through a large vein in the chest area), rather than through the gastrointestinal tract (stomach or bowel) like in enteral feeding. A central line or peripherally-inserted central catheter (PICC) line is inserted and feeds are given through a port. TPN is higher risk than enteral feeding. Strict aseptic procedures have to be followed when connecting feeds or touching the site as there are risks of serious infections and sepsis.

Tracheostomy care

A tracheostomy is an artificial opening into the windpipe (trachea) which is held open by a tracheostomy tube. It helps children to breathe. Air goes in and out through the tracheostomy tube and bypasses the nose and mouth. Family carers who care for a child with a tracheostomy learn to perform various tasks, this includes: removing excess secretions by suctioning, changing the tapes which hold the tracheostomy tube in place, caring for the skin around the stoma site and organising equipment and supplies. Some children who have tracheostomies may also need the help of a ventilator (invasive ventilation).

Nasal cannula delivered oxygen

Oxygen therapy involves breathing in air from a machine which contains more oxygen than normal air. Nasal-cannula therapy is common way of delivering oxygen. The oxygen is administered through a tube that sits at the opening of the nose.

Bowel washouts

A thin tube is inserted into the child's bottom and filled with a warm saltwater solution. This softens the faeces and flushes it from the child's bowel.

Anal dilations

If a child has had a new anus created or widened, in some cases, parents are asked to stretch (dilate) it using a probe called a dilator. Anal dilation is needed to keep the child's anus open to the right size. This is typically done once or twice a day. Dilations are continued until the rectum has completely healed and has reached a desired size.

Stoma care

Some children need a stoma which is an artificial opening for the bowel. Faeces go into an external pouch called a stoma bag. Stoma bags have to be emptied and changed several times a day.

13.6 Appendix 6: List of charities who advertised Survey 1 and Survey 2 (Chapter 6)

Below is a list of charities who advertised the surveys.

	First survey	Second survey
Well Child	✓	✓
TOFS	✓	✓
Together for Short Lives	✓	✓
Cerebra	✓	
Cystic Fibrosis Trust	✓	
Special Kids in the UK	✓	
Flexicare	✓	✓
Viking House, Barnados	✓	
Helen & Douglas House		✓

For the second survey, our parent representative also posted in the Facebook support group “Blended Diet UK” and “Tube Feeding your child in the UK- support group”.

Some parents also choose to share the survey with friends and family members.

13.7 Appendix 7: Lists of types of specialist care used as an inclusion criteria for Survey 1 (Chapter 6)

Feeding tubes

☐ Nasogastric feeding tubes (NG): giving feeds and/or medications

☐ Nasogastric feeding tubes (NG): inserting/passing new NG tubes

☐ Gastrostomy (e.g. PEG/button): giving feeds and/or medications, care of the skin around the gastrostomy etc.

☐ Gastrostomy: inserting new buttons

Ventilation

☐ Non-invasive ventilation (e.g. via face mask or nasal cannulae/nasal pillows)

☐ Ventilation via a tracheostomy: ventilation, care of skin around site, tracheostomy suctioning, changes of tracheotomy tie, etc.

☐ Routine changing of a tracheostomy tube

☐ Changing ventilation settings (e.g. pressure or rate)

Suctioning

☐ Nasal suctioning

☐ Oral suctioning

☐ Deep suctioning

Bladder and bowel care

☐ Intermittent catheter management (catheters inserted several times a day)

☐ Indwelling catheter management (catheters left in place)

☐ Enemas or bowel washouts

☐ Bladder washouts

Injections

☐ Subcutaneous injection (injections into the fatty layer of tissue under the skin, e.g. insulin)

☐ Intravenous injections (injections into the veins, e.g. IV antibiotics)

Oxygen

☐ Oxygen or high flow nasal cannula therapy

13.8 Appendix 8: Demographics and background information about the families who completed the first survey (Chapter 6)

Table 13.1 Demographics and background information about the families who completed Survey 1

		N (%)
Child's age		
	0-4	10 (24%)
	5-10	17 (41%)
	11-16	10 (24%)
	17-25	3 (7%)
	Not disclosed	1 (2%)
Relationship to Child		
	Mother	38 (93%)
	Father	2 (5%)
	Aunt	1 (2%)
Number of adults living in the household		
	1	5 (12%)
	2	36 (88%)
Number of children living in the household		
	1	11 (27%)
	2	19 (46%)
	3	5 (12%)
	4	2 (5%)
	5	4 (10%)
Number of secondary family carers who help		
	0	6 (15%)
	1	26 (63%)
	2	7 (17%)
	3	2 (5%)
Family carers with a professional background in healthcare		
	Yes	10 (24%)*
	No	31 (76%)
Experience caring for another relative		
	Yes	5 (12%)**

	No	36 (88%)
Help from paid carers		
	Yes	24 (59%)
	No	17 (41%)
Number of different healthcare tasks parents do	1-3	13 (32%)
	4-6	14 (34%)
	7-9	6 (15%)
	10-12	4 (10%)
	13-15	2 (5%)
	16-18	2 (5%)

*Note this includes 5 qualified nurses
** Note this includes other children, wives/husbands and grandparents.

13.9 Appendix 9: Participants' recommendations for topics for videos (Chapter 6)

Participants were asked to rate various topics for videos on a three point scale with 1 indicating 'not very helpful' and 3 indicating 'very helpful'. The vast majority of topics were rated as 'very helpful', with the lowest mean score being 2.45 (see Table 13.2). Topics related to problem solving were generally rated as slightly more helpful than routine care.

Table 13.2 Participants' rating of which topics would be most helpful to cover in videos

	M (SD)	Very helpful	Quite helpful	Not very helpful	Not applicable
What to do if the tube comes out	2.90 (0.3)	129 (88%)	13 (9%)	1 (1%)	3 (2%)
What to do if the tube blocks	2.86 (0.4)	126 (86%)	17 (12%)	1 (1%)	2 (1%)
How to change a gastrostomy button	2.84 (0.4)	118 (81%)	18 (12%)	2 (1%)	8 (5%)
Venting (letting air or gas out)	2.82 (0.4)	114 (78%)	23 (16%)	1 (1%)	8 (5%)
Changing the water in the balloon of the gastrostomy button	2.79 (0.4)	110 (75%)	27 (18%)	1 (1%)	8 (5%)
Advice for new parents from more experienced parents	2.76 (0.5)	115 (79%)	27 (18%)	4 (3%)	0 (0%)
Caring for the stoma/gastrostomy site	2.72 (0.5)	106 (73%)	37 (25%)	1 (1%)	2 (1%)
Tips for managing child's distress (e.g. when changing button)	2.63 (0.6)	100 (68%)	37 (25%)	8 (5%)	1 (1%)
Giving a feed	2.63 (0.5)	94 (64%)	48 (33%)	3 (2%)	1 (1%)

Giving medications	2.62 (0.5)	93 (64%)	50 (34%)	3 (2%)	0 (0%)
Recommendations of Facebook groups to join for support	2.49 (0.6)	82 (56%)	52 (36%)	11 (8%)	1 (1%)
Flushing the tube	2.45 (0.6)	76 (52%)	57 (39%)	11 (7.6%)	2 (1%)

13.9.1 Family carers' suggestions of other topics to include

Family carers had various suggestions for other topics for videos. Common technical topics included blended diet, tips for specific problems (e.g. replacing connector end of Freka peg) and different types of feeding tubes. They also had suggestions relating to wider support needs, including advice on doing daily activities, ways of explaining feeding tubes to children and siblings and reassuring other families that children can still do normal activities: "*Showing people that they can get out and about with their child still. I know parents who return home to feed their child it would be nice to show how a gtube doesn't stop fun*."

13.10 Appendix 10: Flowcharts showing participants excluded for poor compliance and participant drop-out by session and condition in experiments (Chapters 7, 8 & 9)

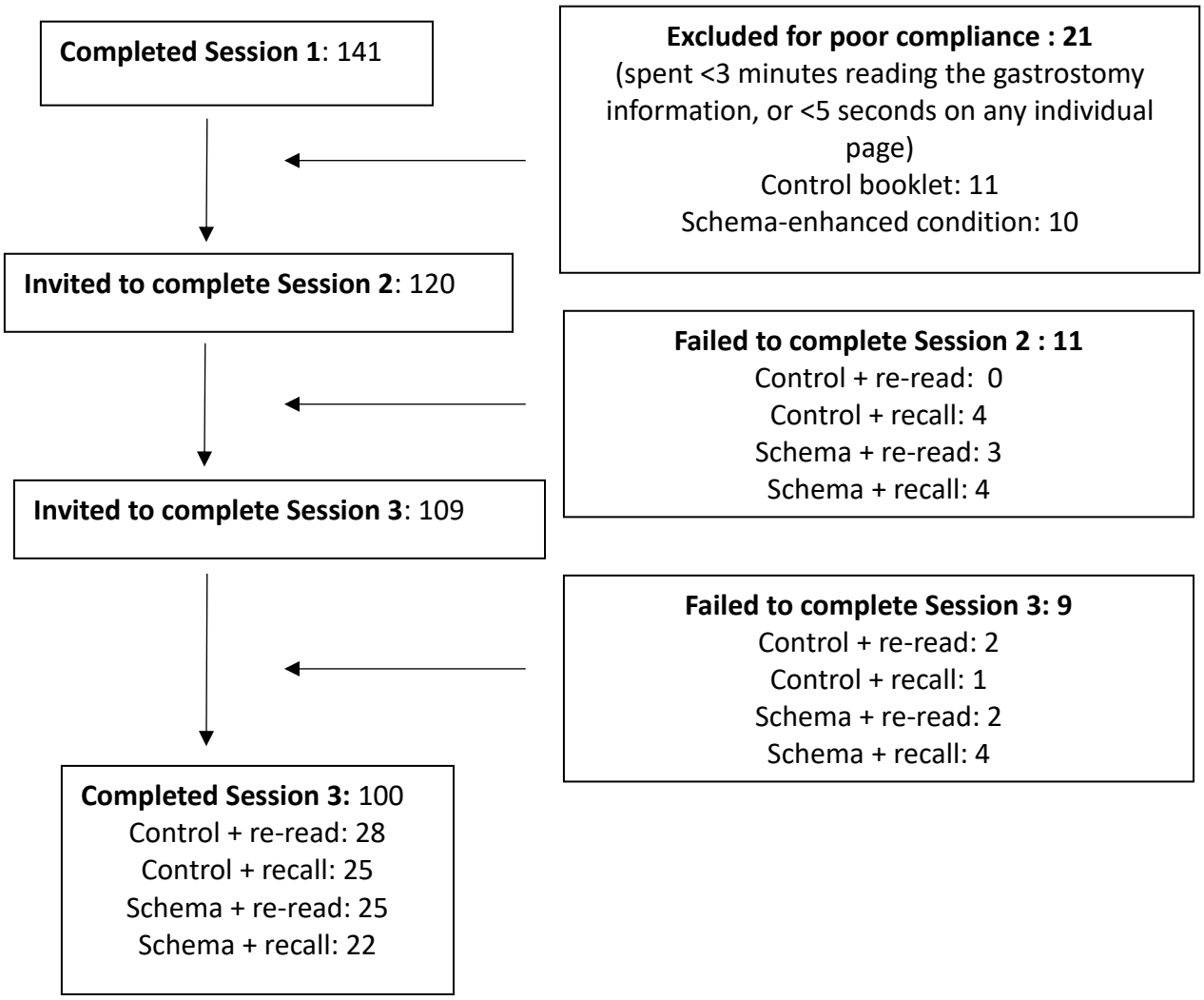


Figure 13.1 Flowchart illustrating participant dropout/exclusion for Experiment 1 (Chapter 7)

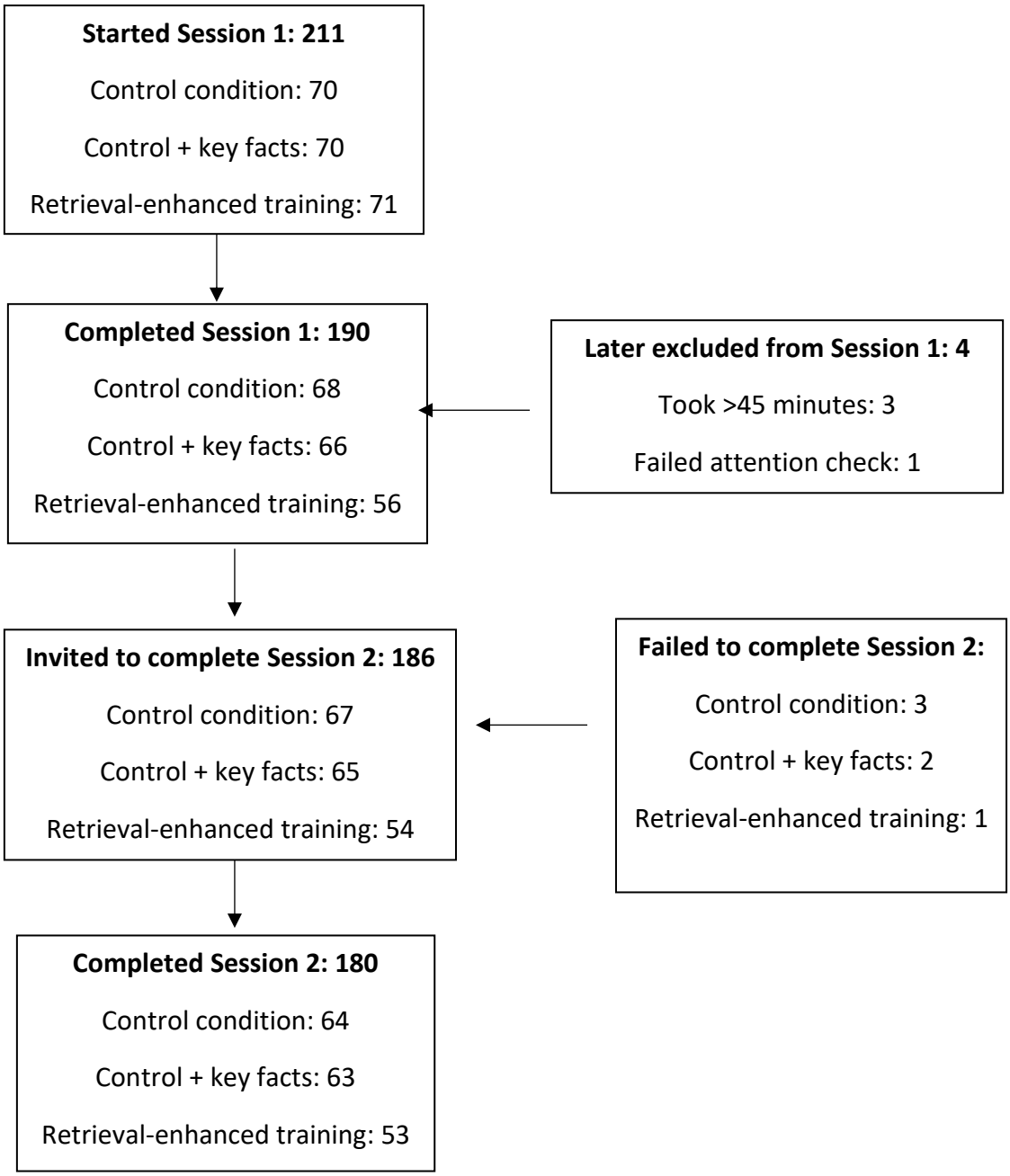


Figure 13.2 Flow chart illustrating participant dropout/exclusion for Experiment 2 (Chapter 8)

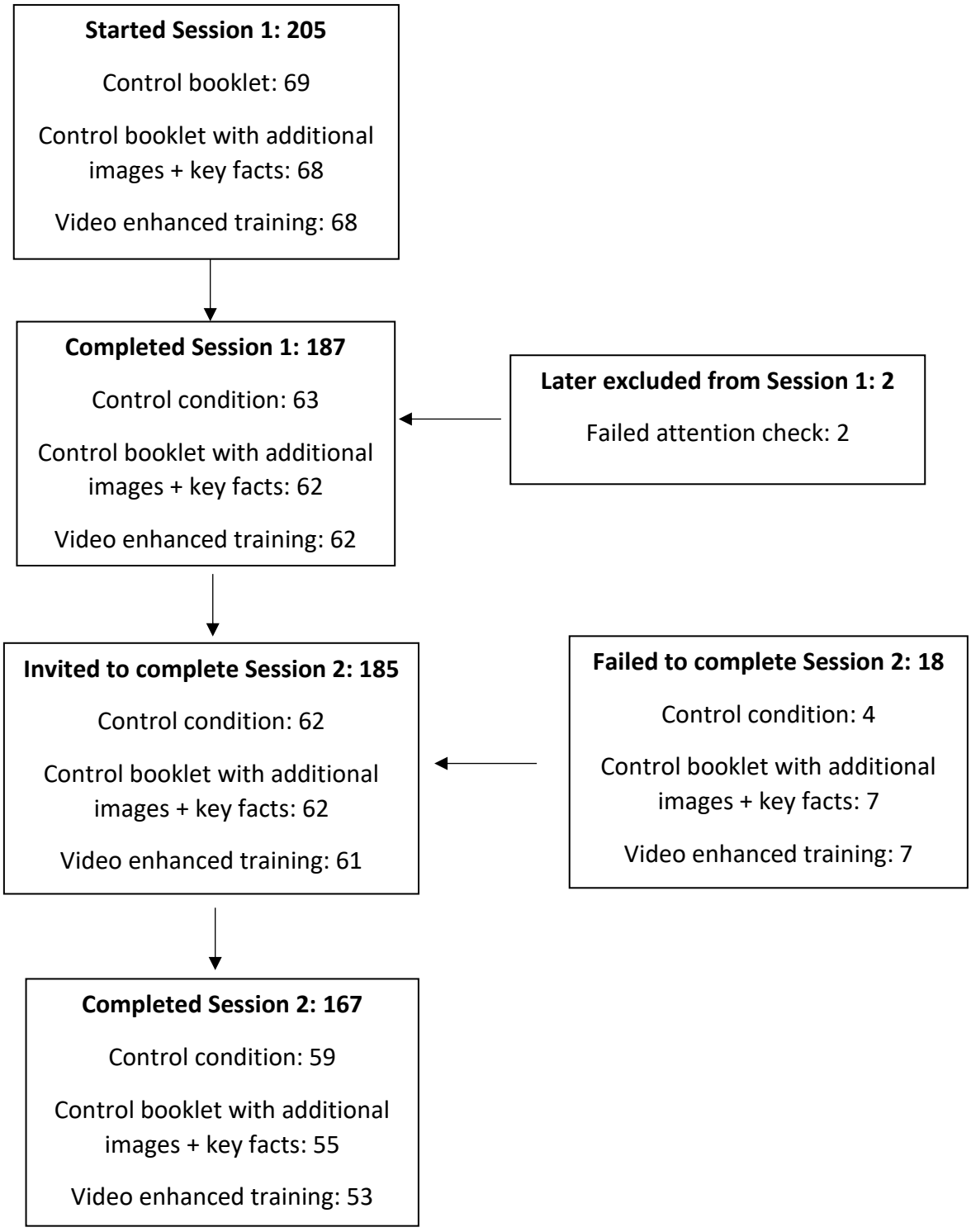


Figure 13.3 Flow chart illustrating participant dropout/exclusion for the video experiment (Chapter 9)

13.11 Appendix 11: Exploratory analyses on wrong or 'dangerous' answers vs. blank answers for Experiment 1 (Chapter 7)

In the real world context of training parents to care for children with feeding tubes, it would be much more dangerous to act on something potentially dangerous (e.g. giving a child a feed through a misplaced PEG tube) rather than know that you do not know what to do, and contact a healthcare professional for help. In the analyses for the primary outcome measure (scores on the cued-recall test), both wrong answers and blank answers were both scored as '0'. In order to differentiate between wrong answers and answers left blank, I introduced negative scoring, coding blank answers as '0', wrong answers as '-1' and answers demonstrating serious misconceptions or potentially clinically dangerous answers as '-2'.

13.11.1 Clinically dangerous answers

54% of participants did not give any clinically dangerous answers, 19% gave one dangerous answer, 16% two and 11% gave three or more. The mean number of dangerous answers was highest in the schema and re-read group (M = 1.24, SD = 1.16), followed by control and re-read (M = 0.89, SD = 1.07) and then control and retrieval (M = 0.80, SD = 1.15). The mean number of dangerous answers was lowest in the schema and retrieval group (M = 0.68, SD = 1.81). Given there were so few dangerous answers, an ANCOVA comparing number of dangerous answers between conditions did not reveal a significant main effect of schema-enhancement or retrieval-enhancement, or a significant interaction (Fs < 1).

13.11.2 Negative scoring to differentiate between wrong and blank answers

I calculated a new score for each participant to account for wrong and dangerous answers vs. blank answers, coding blank answers as '0', wrong answers as '-1' and answers demonstrating serious misconceptions or potentially clinically dangerous answers as '-2'. Total scores ranged from -22 to 35.5, with mean of 13.8. The mean score was numerically highest for participants in the control booklet with re-reading condition (*M* = 16.1, *SD* = 11.0), followed by the schema-enhanced booklet with retrieval practice condition (*M* =15.6, *SD* = 15.0) and the control booklet with retrieval practice condition (*M* = 15.0, *SD* = 9.8). Performance was lowest for participants in the schema-enhanced booklet with re-reading condition (*M* = 8.6, *SD* = 10.0).

In order to assess whether there were any significant differences cued free-recall scores with negative scoring, I ran a 2 x 2 analysis of variance (ANCOVA), with schema-enhancement (control booklet vs. schema-enhanced) and retrieval-enhancement (retrieval-enhanced vs. re-read) as independent variables, cued free-recall score as the dependent variable and general memory score included as a covariate. There was no significant main effect of schema-enhancement (*M* = 11.9 *SD* = 10.3) vs. control (*M* = 15.6, *SD* = 12.9) on the cued free recall test; F(1,95) = 3.27, *p* = 0.07, ηp^2 = 0.03. There was no significant main effect of retrieval-enhancement (*M* = 15.3, *SD* = 12.3) vs. re-read (*M* = 12.5 *SD* = 11.1) on performance in the cued free recall test; F(1,95) = 1.87, *p* = 0.18, ηp^2= 0.01. The effect of the memory covariate was significant, F(1,95) = 6.54, *p* = 0.01, ηp^2 = 0.06. As with the analysis of the primary outcome measure, there was a significant interaction effect on performance in the cued free recall test; F(1,95)= 5.35, *p* = 0.023, ηp^2 = 0.05. Figure 13.4 shows the interaction effect which is driven by poor performance

in the schema and re-read condition. The analyses for negative scoring follow the same pattern as for the initial scoring for the primary outcome measure.

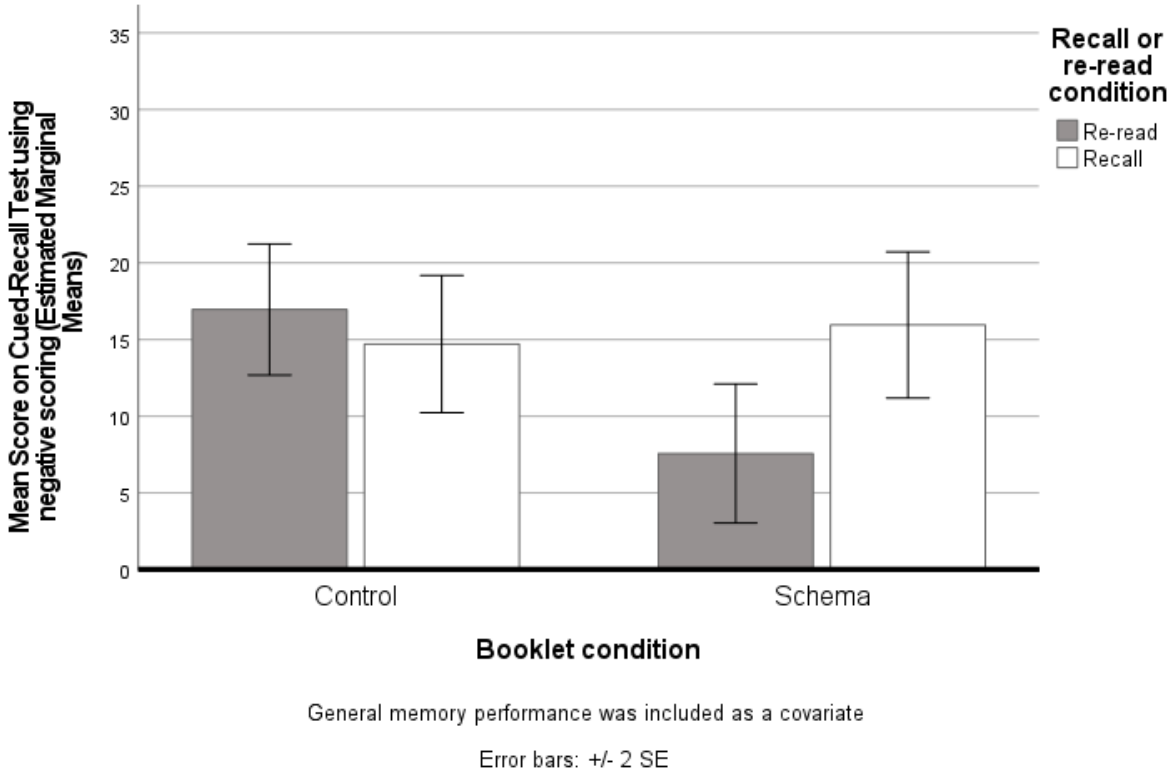


Figure 13.4 Negative scoring for cued-free recall test by booklet condition (control vs. schema-enhanced) and re-read vs. recall

13.12 Appendix 12: Exploring additional outcome measures of interest (Chapter 8)

In my pre-registered analyses I stated that I intended to explore some further outcome measures, in addition to performance on the recognition memory test. The outcome measures explored below are potentially important in the clinical context. Although performance on a recognition memory test is a widely used outcome measure for studies on the testing effect, and easy to score reliably, I wanted to explore whether there may be additional outcome measures which capture some further clinically-important concepts.

13.12.1 Dangerous answers

I ran further exploratory analysis to see if there are differences between conditions in the number of dangerous answers selected (as was explored in the experiment in the previous chapter). There were 10 possible dangerous answers in the recognition memory test: 84 (47%) participants selected none of the dangerous answers, 72 (40%) selected one dangerous, 22 (12.2%) selected two, one (0.6%) selected three dangerous answers and one (0.6%) selected four dangerous answers. No participants selected more than four dangerous answers. The mean number of dangerous answers was less than 1. The number of dangerous answers selected was highest in the control with key facts condition (M = 0.73, SD = 0.70), followed by the retrieval-enhanced training (M = 0.68, SD = 0.83) and lowest in the control condition (M = 0.64, SD = 0.74). I ran a one way ANOVA with type of training as the independent variable and mean number of dangerous answers selected as the dependent variable. There was no significant effect of training on the number of dangerous answers endorsed in the test: F<1. Given most participants only endorsed 1 or no dangerous answers, this outcome measure did not appear to be useful for evaluating differences between conditions.

13.12.2 Calibration between accuracy and confidence: Post Decision Wagering

Retrieval-based interventions have metacognitive benefits, and may plausibly improve the calibration between participants' performance on the test and their self-rated confidence. It would be clinically useful if participants were better calibrated in their abilities, and could contact clinicians when they are unsure (rather than doing something potentially dangerous) and not contact clinicians unnecessarily when they actually know what the correct course of action is.

I used post-decision wagering to assess the calibration between correct/wrong answers and confidence ratings across the three conditions. If a participant had good calibration between confidence and accuracy, they would select low confidence scores for wrong answers and higher confidence scores for correct answers. You would therefore not expect participant to select high confidence levels for answers they got wrong.

In order to assess the calibration between accuracy and confidence, I added up the confidence ratings for all the answers participants got correct (minimum score of 1, maximum score of 7), and subtracted the confidence ratings for all the answers participants got wrong (minimum score of 1, maximum score of 7). The mean score was 31.7 (*SD* = 33.3). The minimum score was -46 and the maximum was 113. Post-decision wagering scores were highest in the retrieval-enhanced condition (*M* = 36.4, *SD* = 34.5), followed by the control and key facts condition (*M* = 35.2, *SD* = 32.9). Scores were lowest in the control condition (*M* = 24.4, *SD* = 32.0). I ran a one way ANOVA with type of training as the independent variable and post-decision wagering score as the dependent variable. There was no significant main effect of type of training on post-decision wagering scores (calibration between confidence and accuracy): $F(2,177) = 2.46$, $p = .09$.

In summary, both the retrieval-enhanced training and the control with key facts condition seemed to lead to improved calibration between accuracy and confidence, however this difference was not statistically reliable.

13.12.3 The calibration between accuracy and confidence: signal detection theory

An alternative method for exploring the calibration between performance on the test and confidence is through signal detection theory, by using receiver operating characteristic (ROC curve). For each person I calculated the area under the curve (AUC) using the 20 multiple choice question answers (correct or wrong) and the associated confidence ratings for each question (on a scale from 1 to 7). I then used the AUC values for each participant to calculate the mean AUC for each type of training. The AUC was highest for the condition with key facts (M = 0.66), followed by the control condition (M = 0.63) and lowest in the retrieval-enhanced condition (M = 0.62). The difference in the AUC values between the three conditions was not significant.

13.13 Appendix 13: List of videos used in the experiment (Chapter 9)

There were seven sections of the written booklet used in each of the conditions. In the video-enhanced condition, each section had an accompanying video. Where there was an existing suitable video made by a healthcare organisation in the UK, I used this video. For the rest of the sections I created videos with local healthcare professionals and families. I later developed a full suite of videos for families which are described and evaluated in the Chapter 10. This experiment covers routine care only (and does not cover topics like troubleshooting and more advanced tasks such as changing a button device).

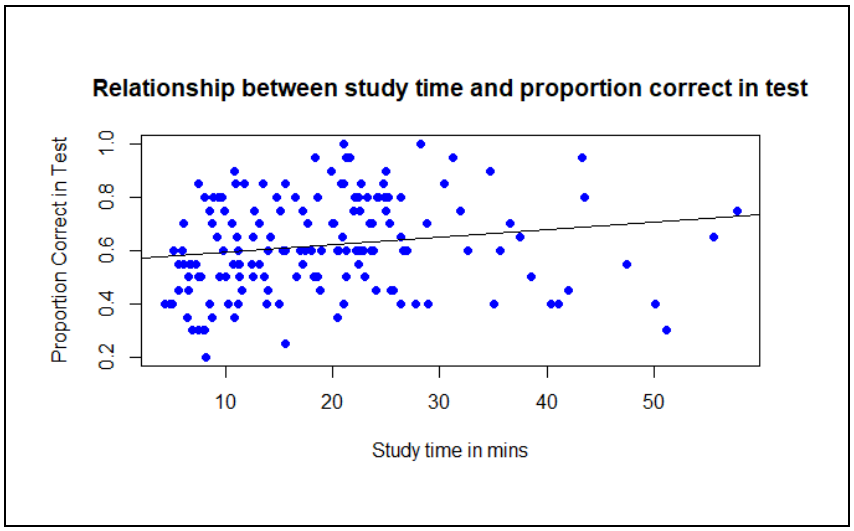
Topics	**Video link**
1. What is a gastrostomy button?	https://youtu.be/Tw8O5ikgRPI
2. Infection control	https://youtu.be/5dlIR6tEcyA
3. Daily care of the gastrostomy button	https://youtu.be/Ql-PmNjewx4
4. Weekly care of the gastrostomy button	https://youtu.be/ivxYK_oMwl4
5. Using a gastrostomy button	https://youtu.be/XRufcmBPwBE
6. Administering a feed	https://youtu.be/vTeSMmcNdiw
7. Administering medication via a button extension	https://youtu.be/_bXiVqjvl7g

13.14 Appendix 14: Relationship between study time and performance in the tests (Chapter 9)

Across all conditions longer study time was positively correlated with higher scores in the recognition memory test (see Figure 13.5). This is consistent with the findings reported in the main text of longer study times and improved memory in the video-enhanced training condition and control condition with additional images and key facts, relative to the training-as-usual control. There was a weak positive relationship between proportion correct and study time for the control booklet and the control booklet with additional images and key facts. There was a weak negative relationship between proportion correct and study time for the video-enhanced training.

For the ordering instructions questions, the effect of type of training on performance in the ordering instructions task remained significant when study time was included as a covariate; $F(2,163) = 4.07$, $p = .02$, $\eta p^2 = .05$. The effect of the study time covariate was not significant; $F<1$.

Together these findings suggest it is not study time that is important for performance on the memory test, but what you do during the study time that matters.



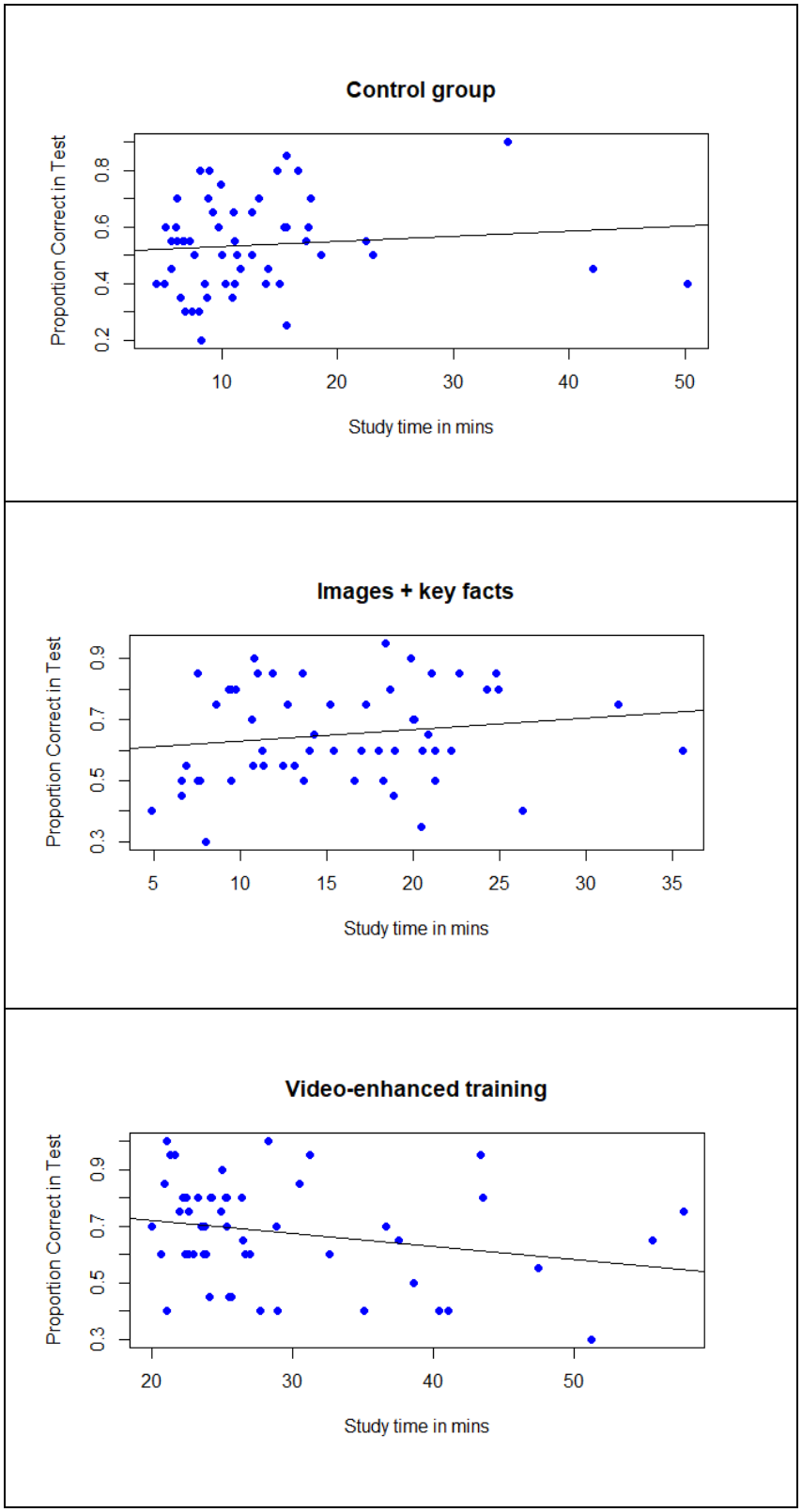


Figure 13.5 Scatterplots showing the relationship between study time and proportion correct in recognition memory test across participants: i) all conditions, ii) control booklet, iii) control booklet with additional images + key facts, and iv) video-enhanced training.

13.15 Appendix 15: Summary of feedback on individual videos (Chapter 10)

1. **Why children need gastrostomies** (https://youtu.be/Uor2XQrP_Ko)

Most of the comments on this video related the short-length or clarity of the video, e.g. "*good clear explanation is provided and in simple terms so that anyone that is not medically minded can understand [family carer]*". There were a few suggestions for extra details, e.g. other less common reasons why children might need gastrostomies, or improvements to the production quality.

2. **Advice and tips from a new parent** (https://youtu.be/bJid9clg0Hs)

Healthcare professionals and families valued hearing directly about a family's experience and tips. One family carer commented: "*I found this video really moving. It was helpful and reassuring to hear about the emotions involved for this family. It made the whole process seem a bit less daunting and more real*." As some family carers remarked, the family's story in the video is not typical of all families: "*Helpful but not relevant to all parents as some children that have complex medical needs would have a very different path for their child*." It could be helpful to film more videos with different families talking about their experiences to increase the diversity of families involved.

3. **About the surgery for a gastrostomy button** (https://youtu.be/wMzi8jLOB5Y)

Most family carers and healthcare professionals commented that the video was clear and informative. Several healthcare professionals commented on the clear definitions: "*Glad to see that complex words are explained. Keeping language simple/layman's terms is so important in these types of videos.*" Some family carers commented that they had learnt new things from the video, although their child had their surgery a long time ago: "*This*

video is REALLY interesting in how the stomach is attached to the tummy wall - our child had issues in this area on one operation so actually really interesting to watch." A few families commented that this was not how all gastrostomy surgery works, and that a different surgical technique was used for their child.

4. **Changing the water in a gastrostomy balloon** (https://youtu.be/9Xw5UpieG_g)

Several healthcare professionals commented that they liked that a parent was doing the teaching in the video, demonstrating on her child at home, with additional diagrams and voiceovers added: "*This is a really lovely combination of the 'real life' setting, with the voice over and the diagrams and text*." There were several comments about the fact sterile water was used in the videos: participants commented that some areas suggest cooled boiled water and some families use tap water. A few families commented on small differences in practice between how they were taught and what the mother in the video does; however these small concerns were not generally raised in the comments by healthcare professionals. For example, a few family carers were concerned the procedure was done with the child on the mother's lap rather than lying on a bed; although the voiceover specifies that it is best when you are learning to do the procedure on a bed, some parents still had concerns. Conversely a few commented that it shows how easy and relaxed the procedure can be: "*I love that this video is done with the child on your lap - it really does show this is an easy procedure and nothing to be scared of."*

5. **What to do if the button comes out** (https://youtu.be/N-sd2n0YNFk)

Several family carers and healthcare professionals commented that this video was clear and reassuring: "*Another really informative video. We currently have NG tube which is always coming out. This has reassured us about the process for if/when the button comes*

out." A few healthcare professionals and family carers commented that they had not previously heard of, or managed to get hold of an 'enplug' device for if the gastrostomy button comes out. There were also a few suggestions about improving the production quality.

6. Granulation tissue

Family carers and professionals alike commented that the video was clear and provided a useful guide to possible treatments. For example, one healthcare professional commented: "*I found this video extremely useful as this is not an uncommon problem and often causes a lot of frustrations amongst all involved."*

13.16 Appendix 16: Healthcare professionals' and family carers' ratings of which videos are most appropriate to watch when

Table 13.3 and Table 13.4 show the number and percentage of participants who rated a particular topic as suitable to watch at the different time points in a parent's journey. In the tables green indicates >60% of respondents and orange indicates >30% but <60%.

Table 13.3 Healthcare professionals' ratings of which topics would be most appropriate to watch when

	When referred to hospital team for a gastrostomy	Around the time of surgery	In the first few weeks at home after surgery	After child has had gastrostomy for a few months or years	Not sure
Introductory videos	32 (97%)	6 (18%)	2 (6%)	0	0
About the surgery and different devices	31 (94%)	17 (52%)	5 (15%)	3 (9%)	0
Advice & tips from parents	17 (52%)	22 (67%)	16 (48%)	4 (12%)	0
Routine care (e.g. how to clean site)	6 (18%)	28 (85%)	22 (67%)	7 (21%)	0
Troubleshooting (e.g. over-granulation)	3 (9%)	13 (39%)	31 (94%)	14 (42%)	0
Changing a button	4 (12%)	12 (36%)	23 (70%)	17 (52%)	0
Blended diet	11 (33%)	8 (24%)	15 (45%)	24 (73%)	4 (12%)

Table 13.4 Family carers' ratings of which videos would be most appropriate to watch when

	When referred to hospital team for a gastrostomy	Around the time of surgery	In the first few weeks at home after surgery	After child has had gastrostomy for a few months or years	Not sure
Introductory videos	39 (93%)	19 (45%)	9 (21%)	4 (10%)	1 (2%)
About the surgery and	35 (83%)	20 (47%)	5 (12%)	4 (10%)	1 (2%)

different devices					
Advice & tips from parents	18 (43%)	28 (67%)	25 (60%)	7 (17%)	1 (2%)
Routine care (e.g. how to clean site)	8 (19%)	29 (69%)	28 (67%)	8 (19%)	1 (2%)
Troubleshooting (e.g. overgranulation)	7 (17%)	13 (31%)	34 (81%)	16 (38%)	1 (2%)
Changing a button	8 (19%)	14 (33%)	27 (64%)	21 (57%)	1 (2%)
Blended diet	23 (55%)	10 (24%)	18 (43%)	21 (50%)	6 (14%)

13.17 Appendix 17: Final publications and presentations arising from this thesis

Peer reviewed papers:

Page, B., Nawaz, R., Haden, S., Vincent, C., & Lee, A. C. (2019). Paediatric enteral feeding at home: an analysis of patient safety incidents. *Archives of Disease in Childhood*, 104(12), 1174-1180.

Nawaz, R. F., **Page, B.,** Harrop, E., & Vincent, C. A. (2020). Analysis of paediatric long-term ventilation incidents in the community. *Archives of Disease in Childhood*, 105(5), 446-451.

Page, B. F., Hinton, L., Harrop, E., & Vincent., C. (2020). The challenges of caring for children who require complex medical care at home: 'The go between for everyone is the parent and as the parent that's an awful lot of responsibility'. *Health Expectations*, *23*(5), 1144-1154.

Reen, G., **Page, B.** & Oikonomou, E. (2021). Working as an embedded researcher in a healthcare setting: A practical guide for current or prospective embedded researchers. *Journal of Evaluation in Clinical Practice*; 1– 6.

Page, B. Butler, S., Smith, C., Lee, ACH., & Vincent, C., (2021). Training and support for caring for a child's gastrostomy: A survey with family carers. *BMJ Paediatrics Open;* 5 (1) e001068.

Conference Presentations:

Page B, Lee ACH**,** Harrop E, & Vincent C. Developing a training package to prepare and support parents to care for children with complex medical needs. Abstract accepted for oral presentation at 'International Society for Quality in Healthcare Annual Conference (ISQUA)'. *Virtual Conference 2021.*

Page B, Harrop E, Lee ACH & Vincent C. How can we improve training and support for families who do medical procedures at home? Abstract accepted for oral presentation at "Health Services Research UK (HSR UK) Online Conference". *Virtual Conference 2021.* [Video of presentation available on Youtube: https://youtu.be/Mya9poCPz-k]

Page B. Preparation and support for parents who provide complex healthcare. Abstract accepted for oral presentation at 'Improving Patient Safety: new horizons, new perspectives'. *Leeds, October 2019.*

Invited Talks:

Page B. Preparation and support for parents who provide complex healthcare at home. Invited talk at the 'Centre for Healthcare Resilience and Implementation Science (*CHRIS*)'

at the Australian Institute for Health Innovation, Macquarie University. *Sydney, February 2020.*

Page B & Harrop E. Hidden incidents: improving support for parents caring for children with medical complexity. Invited Plenary Talk at 'The Martin House Research Centre 2nd Biennial Research Conference'. *University of York, September 2020.*

Page B & Harrop E**.** Oxford: Promoting safer home care for children with technology dependence. Invited Presentation at 'CoLab conference: through the Complexity Maze'. *Birmingham Children's Hospital, January 2020*.

Page BF. Work in Progress: lessons learnt from engagement with the parent voice. Invited Talk at Well Child's Conference 'Better at Home with Better Care'. *Edge Hill University, June 2018.*

Conference Posters:

Page B, Vincent C, Lee A. Harrop E, Hinton L & Yeung N. Improving preparation and support for parents who care for children with medical complexity at home. Abstract accepted for poster at **'**Royal College of Paediatrics and Child Health 2020 Conference'. *Liverpool, April 2020.*

Page B. Preparation and support for parents who provide complex healthcare. Invited poster at 'TOFS conference' for parents. *Nottingham, October 2019.*

Page BF, Nawaz R, Lee A & Vincent C. Paediatric enteral feeding: an analysis of patient safety incidents in the home. Abstract accepted for poster at 'BSPGHAN Annual Meeting'. *Oxford, January 2019.*